An Exploration of Unusual Beliefs: First Person and Carers' Experiences

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Thesis Overview

Experiencing a ‘delusion’, or unusual belief (UB) is common in the context of a range of neurological and psychological difficulties. For over a century they have been widely studied in many fields and the term has been used to describe many phenomena in which people believe something that is not commonly shared by their wider communities. Despite extensive research exploring the mechanisms by which UBs may occur, less attention has been paid to the experience of those who hold UBs, and the informal carers and supporters who are profoundly affected by them. Exploring experiential accounts of UBs is an important avenue of research to inform effective and acceptable psychological interventions, and reduce barriers to engagement with services.

The first chapter of this thesis is a systematic review. The review aimed to identify peer reviewed qualitative studies exploring first hand experiences of UBs, and systematically review the findings to evaluate where this may complement and enhance current understanding, and inform improved clinical intervention. The aim was established in light of the limited attention to individual qualitative studies, often overlooked in evidence reviews, which results in inattention to experiential narratives and the service users’ voice in the planning and designing of clinical interventions. This review was prepared for submission to Psychology and Psychotherapy: Theory, Research and Practice (Appendix A), selected for its focus on advancing understanding of vulnerability, adjustment and recovery, and cognitive and emotional factors, in relation to psychological difficulties.

The second chapter in this thesis is an empirical grounded theory study. As there is limited understanding of carers’ experiences of UBs, despite the additional burden they present, this study aimed to develop understanding of those experiences. The objective was to develop a model to explain the differences in outcomes for carers, and highlight the factors that underlie acceptance of beliefs. This study was prepared for submission to the British

Journal of Psychology (Appendix B). Having incorporated participants across diagnostic boundaries, this journal was selected due to its approach to incorporating studies that may not fit within the narrow focus of alternative publications, and the inclusion of studies that enhance psychological understanding.

The evidence from the combined studies suggest that people who are experiencing UBs in the context of psychosis are seeking validation of experiences, and support in managing emotions so they can openly explore beliefs. This enables them to integrate personal idiosyncratic explanations for UBs with widely shared and accepted frameworks of understanding to achieve recovery. This necessitates acceptance of unusual ideas and explanations from others.

Some carers are motivated to develop a psychosocial understanding of UBs, which facilitates acceptance. These carers focus on minimising distress and offering supportive listening or dialogue, which meets the needs of the person experiencing UBs. These carers are less likely to experience the high stress and burden, often caused by UBs, and achieve more positive outcomes, while providing the optimum environment for ongoing caregiving or recovery.

Chapter 1

Can first-hand experience accounts of Unusual Beliefs advance psychological theory and practice?

Abstract

Qualitative research has made important contributions to understanding the lived experience of unusual beliefs in psychosis and has the potential to inform psychological theory and clinical practice. This review seeks to bring together the findings of the peer reviewed, inductive research, that explored first-hand accounts of unusual beliefs. A meta-synthesis approach was used. Ten studies met criteria for inclusion. Four themes 'Reflecting on Cause', 'Evolution of Beliefs', 'Experiencing Unusual Beliefs', and 'Recovering' were identified. Central to the themes were the influence of emotion on cognitive processing, and a search for a coherent explanation for confusing experiences. The four themes are discussed in relation to extant literature and implications for clinical practice.

Introduction

'Delusions' or unusual beliefs (UBs) have long been a topic of interest within the fields of psychology and psychiatry, first clearly defined by Jaspers in 1913 (Jaspers, 1963). Contemporary definitions describe 'delusions' as beliefs that are held with certainty, are unchanging in the face of proof or counterargument, and impossible content (American Psychiatric Association, 2013). The reviewer however takes a different view of the idiosyncratic beliefs that evolve in the context of psychosis. There has been an increasing trend that started within survivor groups such as the hearing voices network, to move away from the pathologizing language of psychiatry and 'illness' that does not represent lived experiences, recognise the personal experiences that lead to the evolution of unusual experiences, or acknowledge the purpose and value that can be found within experiences.

This view also sits more comfortably with the reviewer's philosophical stance, in which making sense of the world and experiences is a process of constructing meaning and understanding that occurs in a social context, thus beliefs evolve in response to the interaction of a person with their social world. The term 'unusual beliefs' has been increasingly used as an alternative descriptor in service user groups and the field of psychology (British Psychological Society, 2015), and perhaps more accurately reflects the lived-experience of holding beliefs that have evolved in unusual circumstances and are not shared within the prevailing culture. Rather than reflecting a 'symptom' of an 'illness' that needs to be eradicated to facilitate recovery, UBs reflect a complex process of interactions between a person and their experiences, that needs to be understood while underlying vulnerability is collaboratively addressed. Some studies have suggested, contrary to diagnostic descriptors, that belief content is flexible and amenable to alternative explanation (McCabe, Leudar, & Antaki, 2004; Startup, Pugh, Cordwell, Kingdon, & Freeman, 2015). Furthermore, rather than shared and unusual beliefs representing separate phenomena, they are more realistically represented on a continuum from widely accepted cultural beliefs, to individually held beliefs, (Cox & Cowling, 1989; Peters, Joseph, & Garety, 1999). As formation of all beliefs is a personal, individual, perceptual and cognitive process, non-shared beliefs are not inherently pathological (Georgaca, 2000). UBs are more credibly differentiated by the process and impact of appraisal, the level of distress, and the extent of preoccupation with the belief (Peters, Day, McKenna, & Orbach, 1999).

Studies suggest beliefs are a response to early childhood stress, deprivation, and trauma (Read, Bentall, & Fosse, 2009), with grandiose beliefs related to helplessness and lack of relationships, while persecutory beliefs are linked to abusive experiences (Strand, Olin, & Tidefors, 2015). Adverse experiences and negative life events lead to a system of beliefs in which a person experiences themselves as vulnerable, or bad, the world as unsafe, and others

as hostile, dangerous, or threatening (Bentall, Corcoran, Howard, Blackwood and Kinderman, 2001). Poor relationships and abuse result in an inconsistent sense of self, a negative perspective of others, and difficulties in social functioning, suggesting both attachment difficulties and cognitive factors influence development of UBs (Dickson, Barsky, Kinderman, King, & Taylor, 2016). Low, and unstable self-esteem contributes to formation and maintenance of beliefs (Bentall, Kinderman, & Kaney, 1994), necessitating avoidance of unpleasant thoughts about the self, influencing attributional and reasoning biases (Bentall, et al.,1994; Freeman, Evans and Lister, 2012; Udachina, Varese, Myin-Germeys, & Bentall, 2014), and reducing social connectedness (Quin, Clare, Ryan, & Jackson, 2009). Resultant instability in relationships and isolation increase likelihood of idiosyncratic beliefs, which are thematically linked to life history and current context (Catone, et al., 2016; Dickson, et al, 2016; Read, van Os, Morrison, & Ross, 2005; Read, et al., 2009; Rieff, Castille, Meunzenmaier, & Link, 2012; Rhodes & Jakes, 2000; 2004). One hypothesised link between early experiences and formation of UBs is disturbance in dopamine functioning due to stress and trauma. It is suggested that disruption in dopamine levels alters salience attributed to experiences and reduces confidence in judgments about perceptions in the context of ambiguous stimuli (Broyd, Balzan, Woodward, & Allen, 2017).

Formation and maintenance of UBs is associated with inwardly focussed attention, effortful coping, and alterations in sensory perceptions and self-monitoring (Postmes, Sno, Goedhart, van der Stel, Heering, & de Haan, 2014; Bovet & Parnas 1993, Stanghellini, Ballerini, Poli, & Cutting, 2012; Stanghelli, et al., 2014), intolerance of uncertainty, (Broome, et al, 2007), difficulties mentalising (Corcoran, Mercer, & Frith 1995; Frith & Corcoran, 1996) and external attribution, for sensory experiences (Kaney & Bentall, 1989). Awareness of differences in perceptions is often maintained (McCabe, et al., 2004) and efforts are made to use this awareness to test beliefs and assumptions (Anderson, 2014; Startup, et al., 2015).

Increased suicidal ideation was associated with persecutory beliefs, as people experience negative self-cognitions and schema, low self-compassion, low self-esteem and beliefs of inferiority (Collet, Pugh, Waite & Freeman, 2016). However, some find belief content helpful (Strand, et al., 2015) or see their beliefs as a unique gift, and live at optimum wellness regardless of their experiences (Anderson, 2014).

Predisposing factors, emotion, appraisal of internal and external events, and cognitive biases are brought together in a single model (Garety & Freeman, 2013). The model illustrates these influences on the search for understanding and meaning, alongside social withdrawal, disrupting the usual process of developing socially constructed meaning (Garety & Freeman, 2013). This model provides a comprehensive framework of understanding of the development and maintenance of persecutory UBs; however, the comprehensive underpinnings are based on quantitative research. First-person qualitative studies contribute new perspectives which are often overlooked for the purposes of developing evidence based practice, leaving the voices of the 'experts-by experience' underrepresented. While quantitative studies contribute many robust models, hypotheses and interventions, the first-person perspective is essential in contributing understanding of why people develop difficulties. It aids clarity in how experiences manifest, how people make sense of and live with experiences, and what is helpful in terms of intervention. This perspective facilitates delivery of appropriately timed, collaborative, acceptable approaches and this review aims to draw together a range of first-person experiences to inform clinical practice.

Method

Studies were identified that used qualitative methodology examining some aspect of the experience of UBs. The inclusion criteria were; studies reporting on first-person accounts of UBs; studies written or fully translated into the English language; studies published in a

peer reviewed journal; and studies using qualitative methodology. Exclusion criteria included; studies not reporting on UBs in the context of psychosis, studies not using a recognised qualitative methodology, (e.g. single case studies) studies utilising pseudo-qualitative analysis, that are described as, and resemble qualitative studies, but do not follow recognised or transparent analytic processes (such as studies that did not incorporate first-person quotes, or studies that reviewed narratives to generate categories, or indicate frequency of UB experiences). Papers where first-person experiential accounts were not able to be discriminated from other perspectives, or where analysis did not demonstrate inductive methodology were also excluded.

Papers were identified by searching Web of Science, Scopus, Discover, Medline and Psychinfo databases. Search terms for each database are provided in table 1. Relevant psychosis journals and references in relevant papers were also searched. The screening process is illustrated in figure 1. Studies were excluded if they were from a source other than health, psychology or psychiatry journals and duplicates were removed. Article titles were reviewed with an inclusive strategy. Abstracts were reviewed and papers were excluded that did meet inclusion criteria. Full text review of 97 articles resulted in 12 papers meeting inclusion criteria. Two papers were screened out during the quality review.

Table 1. *Terms used for database searches*

Database	Search Terms
DISCOVER	Delusion* OR “unusual belief*” AND thematic OR qualitative OR "in#depth interview" OR interpretiv* OR transcri* or "focus#group" OR "grounded#theory" OR hermenueti* OR "open#ended" OR "narrative"
MEDLINE	((delusion* or "unusual belief*") and (thematic or qualitative or "in depth interview" or interpretiv* or transcri* or "focus group" or "grounded theory" or hermenueti* or "open ended" or "narrative")).af.
PSYCINFO	Delusion* OR “unusual belief*” Methodology: Qualitative
SCOPUS	Delusion* OR “unusual belief*” AND “Qualitative”
Web of Science	TOPIC: (delusion* OR ("unusual belief*" AND ((((((((((qualitative OR "mixed method") OR interview) OR interpret*) OR hermeneu*) OR "grounded theory") OR narrative) OR "focus group") OR interview) OR thematic) OR transcribed) OR "first person")))

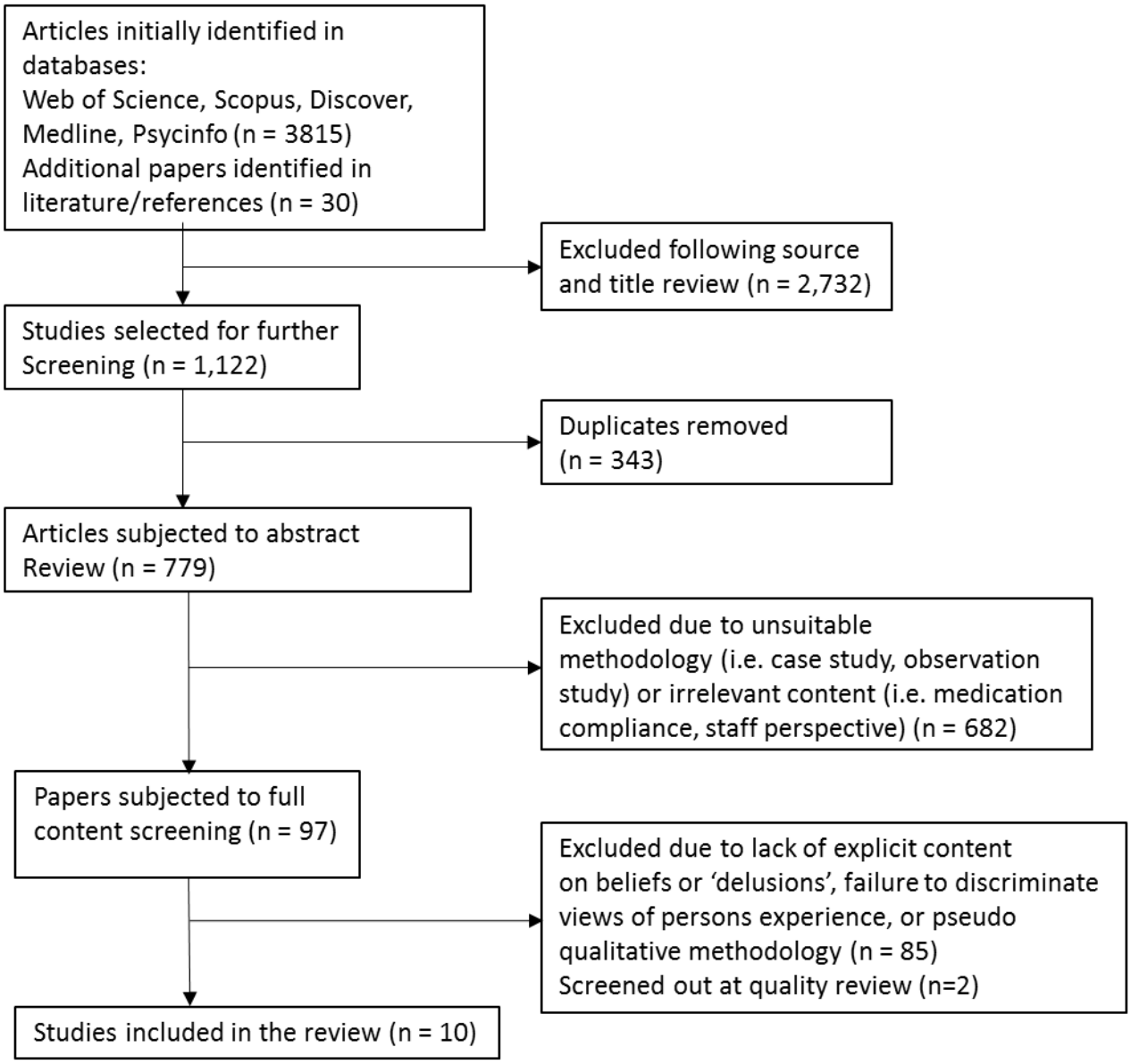

Figure 1. Flow Diagram illustrating identification of papers

The quality analysis criteria outlined by Walsh and Downe (2006) provides a comprehensive structure for assessing eight stages of the qualitative research. Papers considered for inclusion scored a minimum of 9 on the 12 point assessment criteria (Appendix C). Two papers were screened out, due to limited evidence reported to support specific findings on UBs, utilisation mixed qualitative approaches and limited description of

the methods of analysis. One study reported on the topic of how people cope with, and interact with their 'illness' and one paper reported on the impact of 'illness' on social experiences. This resulted in fewer papers contributing evidence to the review, however due to the limited content on UBs, and content overlapping with included studies, it is not thought to have unduly impacted the findings. Individual scores of included studies, alongside study characteristics are outlined in table 2. Details of quality assessments for each study can be found in appendix D.

Method of analysis followed the thematic-synthesis procedure of Thomas and Harden (2008). Papers were read to identify ideas and concepts across studies. Subsequently a process of line by line coding was followed by the development of descriptive themes which summarise the content. The final stage involves the generation of analytical themes to generate new interpretative constructs and hypotheses (Appendix E). Analysis incorporated all reported findings, including those stated in results and discussions within primary studies. The aim is to retain the original meaning while developing new interpretations of the amassed data.

A reflexive analytic approach, was adopted to consider preconceptions and expectations based on previous training and clinical practice. A reflexive approach required consideration of models familiar to the researcher and regularly used in clinical practice. Models were held in mind while coding and developing categories, to ensure that pre-existing knowledge of UBs was not driving the direction of analysis, and to ensure that familiar data or concepts were not overvalued, which may have resulted in replication of extant models. Validity of analysis was checked by the primary supervisor, and themes were explored and modified through discussion. Internal validity is demonstrated through illustrative quotes in table 4, and external validity by cross checking with extant quantitative literature.

Table 2. *Data extraction and quality assessment scores for included studies*

Author	Method & Analysis	Phenomena	Setting	Geography & Diversity	Participants	Themes of analysis	Quality Assessment Score
Boyd & Gumley (2007)	Grounded Theory (GT)	Experiential perspective on developing paranoia	Community, rehabilitation and inpatient	UK Not reported	9 male and 1 female participants aged 26 to 51 experiencing paranoia	Main: Fear, vulnerability Sub themes: Confusion, uncertainty, self under attack	9/12
Campbell & Morrison (2007)	IPA	Subjective experience, trauma & appraisals With & without psychiatric history	Community	UK White British	5 male, and 1 female participants experiencing paranoia with a mean age of 35.7 years	Main: Influences and consequences Sub themes: Feelings of control	9/12
Drinnan & Lavendar (2004)	GT principles of analysis	Interaction of religious beliefs and religious delusions	Community	UK 5 White British 1 White European 1 Afro Caribbean	6 male, 1 female participants aged 30 to 53 experiencing religious delusions	Main: Religious beliefs related to content, but delusions more influenced by family processes (conflict/loss) Sub themes: Identification and wish fulfilment	11/12
Engqvuist & Nilsson (2013)	Content Analysis	First days of postpartum psychosis from multiple perspectives	Community	Sweden Not reported	13 postpartum women aged 27 to 32 with experience of postpartum psychosis	Unwanted baby, infanticide	10/12
Jones, et al. (2016)	Constructivist GT	Negotiating cultural and clinical tensions between the real and delusional, and the sacred and secular	Community	USA Caucasian 13 African American 3 Latino/a 1 Asian or Asian American 1 Multiracial 1	9 male, 10 female participants aged 19 to 78 with experience of unusual religious beliefs	Main: People invoke both science & religion in sense making Sub theme: Awareness of cultural tensions between secular and non secular doubt (and clinical)	9/12

Author	Method & Analysis	Phenomena	Setting	Geography & Diversity	Participants	Themes of analysis	Quality Assessment Score
Larsen (2004)	Ethnographic – inductive analysis of longitudinal interview transcripts	Generating meaning following experiences of psychosis	Community	Denmark Not reported	15 participants with experience of unusual beliefs	Main: Delusions are derived from cultural repertoire Sub theme: Delusions are constructed as dogmatic explanations that are idiosyncratic to the individual	10/12
Rhodes & Jakes (2004)	Case series "qualitative" Grounded & inductive analysis	Metaphorical thinking in delusions – how ideas formed and experiences relevant to beliefs	Community	UK Not reported	15 male, 10 female participants age 25 to 66 with experience of unusual beliefs excluding paranoia	Main: How metaphors contribute to formation of delusions Sub themes: Delusional statements are intended to be literal statements, but report on experiences transformed by metaphorical meaning.	9/12
Rhodes & Jakes (2010)	IPA	First person perspective of delusions	Community – urban areas	UK White 11 Black mixed race 2 Black British 10 Asian 3 Middle-eastern 3	16 male, 12 female participants with a mean age of 37 years and 10 months experiencing a range of unusual beliefs	Main: 3 types of onset identified: eruptive, progressive, and originating in childhood	11/12
Rieben, et al. (2013)	GT	how patients with delusions with religious contents conceptualized or experienced their spirituality and religiousness	Community	Switzerland 92% white European	68 participants 7% of whom were male with a mean age of 42 years with experience of unusual religious beliefs	Main: Religious delusions incorporate: ''spiritual identity,'' ''meaning of illness,'' and ''spiritual figures.'' Beliefs are under constant reconstruction	11/12
Stopa, et al. (2012)	Thematic Analysis	Fear of others – comparison of experiences in social phobia and persecutory delusions	Community	UK Not reported	9 male participants with experience of paranoia	Main: Experience of threat, reactions while under threat, and subsequent reflections Sub themes: Narrative coherence, ability to stand back from the threat following the event	11/12

Results

Four themes were identified regarding experiences of UBs, incorporating 1) reflections on cause (negative life events, substance misuse, vulnerable and bad self, the influence of cultural context); 2) evolution of beliefs (making sense of discomfort, thinking and reasoning, integrating experiences, isolation); 3) experiencing beliefs (purpose, positive v negative experiences, overwhelming and out of control experience, recognising unusual qualities); and 4) recovering (searching for validation, coping, and making sense of experiences). Distribution of themes is shown in table 3. Quotes illustrating themes are shown in table 4.

Theme 1: Reflections on cause

The first theme reflected participants' views on why they may be experiencing UBs. Adverse events and experiences from childhood and adulthood were linked to feelings of vulnerability and a view of the self as bad. Across the lifespan, cultural and social environments shaped identity and frames of reference for making sense of the world.

Negative life events. Difficult childhood circumstances including domestic violence, abuse and neglect were present in accounts. Experiences continued to resonate with feelings of fear and alertness to threat. Negative implied or actual judgement from others, left people with sense of being bad or weak, that shaped their sense of self. Life events in adulthood contributed to the development of UBs, including relationship breakdowns, experiences in the armed forces, and involvement with dangerous people in local communities. Often multiple sequential events occurred over time leading to chronic stress.

Table 3. *Distribution of descriptive and analytical themes*

	References									
Analytical and descriptive themes	Boyd & Gumley, 2007	Campbell & Morrison, 2007	Drinnan & Lavendar, 2004	Engqvuist & Nilsson, 2013	Jones et al. 2016	Larsen, 2004	Rhodes & Jakes, 2004	Rhodes & Jakes, 2010	Rieben, et al. 2013	Stopa et al. 2012
Reflections on cause										
Negative life events	X	X	X	X		X	X	X	X	
Substance misuse	X								X	
Vulnerable & bad self	X	X	X	X			X	X	X	X
The influence of cultural context	X	X	X	X	X	X	X	X	X	
Evolution of unusual beliefs										
Making sense of discomfort	X	X	X	X		X	X	X	X	X
Reasoning and thinking style	X	X	X		X	X	X	X	X	X
Integrating experiences	X	X	X	X	X	X	X	X	X	X
Reasoning in isolation	X	X			X	X	X		X	X
The experience of beliefs										
Purpose of beliefs	X	X	X		X	X	X	X	X	
Positive v negative experiences	X	X	X	X		X	X	X	X	X
Overwhelming and out of control experience	X	X		X	X	X			X	X
Recognising unusual qualities	X				X					X
Recovering										
Searching for validation	X		X		X	X	X			
Coping		X	X		X	X	X		X	X
Making sense of experiences	X	X	X		X	X	X		X	X

Table 4. *Quotes illustrating themes of analysis*

Analytical and descriptive themes	*Participants' quotes*	Authors' explanations and findings
Reflecting on the cause		
Negative life experiences	'*I wouldn't say only s****bags get paranoid, I would just say frightened people. I think get people paranoid because of the way they are brought up. They might be brought up viciously.'* *' I relate that to my experiences of Ireland (soldier). When I got back from there I was feeling really paranoid about everything'.* *'My brother has nothing to do with his da because he battered my ma. So, that just kinda', it's no just drugs when I was growing up I had a whole kettle of fish in childhood with a broken family and my ma and da fighting, that sort of thing, I seen that growing up'*	Indeed, several participants… spoke of being violently assaulted as adults and children. Paranoia was an adaptive response to these violent environments; it kept participants safe If we add together those who described difficulties spontaneously to those who described problems when prompted, then the total is 26 (93%).
Substance misuse	*'I begun to take street drugs and I felt almighty'* *'You open some chambers in your brain which say that this chamber I normally can't use, that is, when I am normal. But you can use it when you have taken mushrooms, then you can use this chamber, because the brain is capable of more than you think'* *'what I would relate to is my experience with cannabis, that was the first time that the word had come into my vocabulary or that I'd heard it and it would be a kind of easy way to describe completely how I was feeling and it wasn't until reflecting on it that I realised that it actually was paranoia'*	Many participants felt that drugs, and cannabis in particular contributed to paranoia. Frank told me that he was convinced that his psychosis had been triggered by his extensive use of drugs.
Vulnerable & bad self	*'that's the thing, I didn't realise that it was paranoia but I was terrified that people would laugh at me or ridicule me or hurt me or trick me in someway'* *'I mean, I, as you know I tend to think that people think I'm evil anyway... or I'm perverted or disgusting, filthy, all these things, smelly, revolting...'* *'I'm gonna let all the dirt and the filth out and what I was going – what I've been through an' 'cause you, uh well I do, I feel very dirty inside.'*	The consistent finding was that everyone who is paranoid is frightened and vulnerable, feels confused and uncertain and that they are under attack.

Analytical and descriptive themes	*Participants' quotes*	Authors' explanations and findings
The influence of cultural context	*'I feel as though I have passed on information to the relevant intelligence organisation through the quiz I do on a Monday evening. I felt threatened that the IRA knew where I was.'* *'I didn't really believe in God. I definitely didn't believe in the devil. It seems like when this happened, everything that I've kind of acquired through the cultural influence, came back to me. I don't know if it's just my way of conceptually grasping this experience'*	Spiritual explanations of extraordinary experiences are part of the cultural repertoire in Danish society, it was also widely publicized and consumed. When asked how this had come about, he spontaneously said that when he had been a child he had been watching cartoon superheroes and... '*wanted to be like them'*
Evolution of beliefs		
Making sense of discomfort	*'It seemed like the sun focused on me. It was 'an orangey colour', 'overwhelming' and there was a 'shhh sound'.* He stated: *I walked down there and the sun appeared to be, err, sort of like hanging'.* From that moment he became terrified '*the physical symptoms, the feeling of being burnt, err. Something was biting my head as well. I had a few occasions where I felt I was being eaten alive.'*	Julie's delusions provided an explanation for interpreting… unpleasant experiences and feelings of being surveyed at work. P7 had received serious burns from boiling water to her lower back and it was on her back that she mainly felt these sensations.
Thinking and reasoning	*'people were out to harm me, not necessarily physically, and I remember having these types of thoughts all over the years but they would be short lived and transient'* *'My brother died when I was a child, I gave him an apple that day, you see? Like Satan.* *'Umm, I just quite worry, I was anxious and I thought the bus driver was looking at me through the mirror to see I was, I was behaving, people around me were aware of it and um, I felt, I was being watched you know and the more I think I'm being watched the worse, the worse it gets.'* *'but when I'm, when I'm ill, you don't, you just accept, accept what you hear and what you think as, as real. No matter if it's complete rubbish, you just think it's true...'*	She gave the behaviour of other people specific interpretations. For example, a busman did not collect her fare because he was too disgusted to approach her. The patient group tended to talk about loose links between events as providing evidence for their beliefs Personalizing… is the tendency to apply events in the world to oneself. The inclination to do this was discussed by both groups and it seemed that this was involved in the development of their paranoid ideas

Analytical and descriptive themes	*Participants' quotes*	Authors' explanations and findings
Integrating experiences	*'I couldn't sleep, days without sleep, but that made me worse. That made me dead down and always everywhere I went I was always looking over my shoulder'* *Well they, they let me know who, who to be on guard against so if 'I'm walking into Tesco's and somebody's coming at me, [the voices] they'll say "it's alright, just keep walking, look straight past them he's gonna be alright" or "she'll be alright" or they'll say "be careful, there's a thing coming", you know somebody with a, a threat, they'll let me know.'* *'I was getting these hallucinations and these shadows and these frightening demonic thoughts and things, people turning into demons.'*	Voices eroded trust in self and others and increased uncertainty. Thus, voices were central to the development of persecutory paranoia. At the beginning it was a mixture of potent emotions (shame, embarrassment, desire for secrecy) and ideas (others spread stories); the initial mixture was present but not dominant until she became increasingly upset and lonely. Voices eroded trust in self and others and increased uncertainty. Thus, voices were central to the development of persecutory paranoia in this sample... Voice hearing also contributed to feeling the self was under attack.
Reasoning in isolation	*'Uh, [I] wear a pair of sunglasses and hide away.'* *'I came from a diabolical family I as a child; I received no love, no trust I I was fed up to be rejected… I was extremely alone'* *'If you don't have a trusted friend to talk to and go: 'that is just ridiculous, what you are talking about' then I think it can build up'*	The framework with which he interprets reality, through its content and structure, generates indestructible convictions and a complete rupture with others and the surrounding world. The participants interviewed for the present study emphasized reactions likely to maintain distress by preventing disconfirmation of beliefs (typically through behavioural or more subtle forms of avoidance). In the absence of an assumed social bedrock, subjects were forced to consciously negotiate their experiences (and the implications of these experiences) in relative social and cultural isolation.
The experience of beliefs Purpose of beliefs	*'I thought I was the Christ I… I have to expiate the world's sins… I was immortal.'* *'The only positive aspect I can actually think of is actually feeling proud perhaps...it did a lot for my confidence'* *'When I am the Messiah, I am very happy. I hear God. He gives me the mission to save the whole world from genocide. I am almighty.'* *'I guess it is good to be a little bit suspicious . . . in the sense that you don't want to kind of throw yourself into something. I guess it protects you from being hurt'*	Religious delusions provided a wished-for relationship for some participants. Paranoia was an adaptive response to these violent environments; it kept participants safe. Many patients explained that they are looking for proximity with a spiritual figure when they are facing distress. More generally, their relation with a spiritual figure allows them to feel less lonely. The need to increase one's strength to defend against others led to grandiose statements and ideas.

Analytical and descriptive themes	*Participants' quotes*	Authors' explanations and findings
Positive v negative experiences	*'Well if life is in three dimensions well you tend to see the fourth dimension, a completely different view of life... able to see life from a different angle'.*	A relation with a spiritual figure might allow patients to develop more secure attachment patterns
	'Well, but if I became God then it must be because I have a message to people.'	Many patients explained that they are looking for proximity with a spiritual figure when they are facing distress. More generally, their relation with a spiritual figure allows them to feel less lonely
	'I don't think that I ever will get any more wild experience, or better experience, or worse experience.'	
	'I tried to kill myself because I wanted to verify if I was immortal and I found myself at the hospital.'	
Overwhelming and out of control	*'You don't know it's happening. It's like a blanket has come over you (pulling hands over face) and you're not seeing the truth'*	Participants reported compelling, often racing streams of thought, and a clear sense of being trapped in these internal events
	'It's a never- ending movie going in a loop, I'm locked up in hell for infinity, I'm stuck in an infernal worm drive'	He is like a devil receiving punishment by God. We speculate that having such extreme content might in itself have intensified his emotional state
	'I was controlled by evil spirits who took over my body.'	
	'It is extremely overwhelming.'	
Recognising unusual qualities	*'I'm aware that a lot of the claims that I'm making are far out, that [they] are hard to accept as being true, but sorry, all I can say is that this is what I believe to have been happening.'*	Virtually all of our participants also noted at least some degree of subtle, but unmistakable, phenomenological incongruence between their "multiple realities".
	'Sometimes it could just be a complete figment I think'.	
Recovering Searching for validation	*'You need to remember it is real to them. It's not real to you but it's real to them.'*	Religion sometimes provided membership of a community where participants' unusual beliefs were welcomed, or at least tolerated.
	'Even if I'm ill, I'm human and God loves all of us.'	Frank said that he would like to have the opportunity to talk to a person who had special knowledge of the spiritual
	'the only thing you can do about it is to listen to some music and talk to your parents, and things like that. Well, it is a bit bleak, you see, in some way. I don't know, maybe you can't expect more'	

Analytical and descriptive themes	*Participants' quotes*	Authors' explanations and findings
Coping	*'Irrespective of what logic or anything else told me still the fear was so real so therefore the belief was still standing so I had to challenge it which I did quite effectively but it was really difficult.'* *'I tried to use all the skills I have to sort of um calm myself and be optimistic um and I was looking to the future.'* *'Well hopefully I've been taught different strategies to cope so, um, I think if, if I'd been taught how to cope, obviously being in and out of hospital, I think I'd be ab- I, that think that situation wouldn't have happened'*	Informants presented varying strategies in the management of their experiences, contrasting recovery styles of "sealing over" and "integration".
Making sense of experiences	*'I'm considering that it might be the medication [making me better]. In that case I've got to start believing that it wasn't demons. And I find that hard to believe.'* *'God brings science forward and guides doctors.''* He says that God helped him to understand that *'...medication and psychotherapy are indispensable to face the symptoms.'* *'God puts us on trial; it's for our own good. He puts hardship on our road; it's up to us to deal with it.'* In her opinion, her illness is a necessary step for her to purge her sins and purify her soul. *'[The idea that I had been clairvoyant] came just after I...I won't say that I had become well, but just after the pills started to work. Then I started to explain to myself what happened to me'*	This research suggested that individuals recovering from severe mental health difficulties draw upon resources to develop an identity preferable to that connoted by the label 'schizophrenic.'. With equal frequency, participants weighed and debated competing secular and supernatural explanations, often juxtaposing and blending different explanatory frameworks. Julie… a year and a half after… still stuck with the delusionary interpretation of events. Eva who 'initially firmly held the biomedical explanation of her experiences… stopped speculating about how her experience might be explained, because she had learned that each explanation repeatedly became falsified by another theory'

Substance misuse. Cannabis and other substances were introduced as likely triggers of UBs by only two participants, despite one paper reflecting very high rates of substance misuse. Cannabis was linked to paranoia. Other substances were related to developing special insights and experiences.

Vulnerable and bad self. Often linked by participants to difficult experiences in childhood, interviewees described themselves in negative terms, such as sinful, dirty, cowardly, bad, weak or abnormal. Many felt compelled to hide aspects of themselves from others leading to isolation. A sense of the self as bad is often reflected in self-critical judgements and feelings of guilt, and therefore being deserving of punishment or attack. Common themes included self-condemnation for perceived flaws, feelings of failure and feeling fearful.

The influence of cultural context. In some case persecutory beliefs seem to have a common connection, either with experiences of violence in the past, or a realistic threat because of contact with drugs and gangs, and local culture. In other cases, a pre-existing interest in, or exposure to the cultural world is linked to the content of beliefs. Concepts of sin, possession by the devil, or special relationships with God are common in the context of religious knowledge and involvement. For others, strong interests in the paranormal and spiritual, superheroes, or science fiction, link with explanations for unusual experiences, and often transformative empowering unusual beliefs.

Theme Two: Evolution of Unusual Beliefs

Several elements appear to contribute to the development of UBs. Often a sense of unease or discomfort in the absence of clear triggers leads to an effort to make sense of the cause. Through the process of sense making, several unusual cognitive processes take place, and a range of experiences (both usual and unusual) are integrated to develop a coherent

narrative. The integration of feelings, sensory experiences, and sometimes voices strengthens and maintains beliefs. Discomfort can result in avoidance and isolation, preventing engagement with alternative perspectives.

Making sense of discomfort. Discomfort occurs prior to and during many experiences of UBs. Unpredictable and sudden changes that are not easily explained result in anxiety, feelings of panic, stress or depression. Uncomfortable thoughts, physical sensations and onset of illness may also trigger a search for meaning and explanation, in the context of intolerably ambiguous and uncertain events.

Thinking and reasoning. A strong theme across papers were differences in thinking and reasoning, which often differentiated shared beliefs from UBs. Shaped knowledge and previous experiences many narratives demonstrated negative bias, and hypervigilance, reflecting feelings of being under threat of physical or emotional harm, and fear of their 'real-self' being revealed and rejected. Loose associations were often made between coincidental or unconnected events creating new meaning, and personalisation led to feeling of being at the centre of events. Being unable to decentre from beliefs and consider alternative explanations was also highlighted and interpreted in one paper as poor metacognitive awareness. Reasoning appeared logical in many cases, but narratives and explanations were often fragmented, and concepts that were loosely held by others were held with certainty and given relevance that would not be shared in the wider community. Reasoning incorporates idiosyncratic meaning and evidence drawn from pre-existing cultural beliefs and interests. Often beliefs can present as though there is a merging of metaphor into experience, such that the persons reality moves from 'it's like being in hell' to 'I am in hell'. The authors of one paper suggest that this 'association' occurs in moments of crisis, and unusual experiences, the self, or the world are transformed by metaphor.

Integrating experiences. Attempting to make sense of unusual experiences and sensations involves drawing together intrapersonal sources of information. Incorporated into the process are intrusive thoughts and images, sensory experiences, emotions, memories, and hearing voices. Attention may be drawn to others, and their behaviour during the process. In the context of persecutory beliefs, throughout the narrative, unexplained anxiety, and aggressive and critical voices were strong themes. Others spoke about tactile hallucinations, unexplained pain, or a sense of unease or anger. Confusion about seemingly inexplicable thoughts, feelings and sensory experiences, and an effort to make sense of them, were central in accounts of developing unusual beliefs.

Reasoning in isolation. A sense of unease in the world and feelings of anxiety or depression encourage isolation to reduce stimuli and manage experiences. In isolation idiosyncratic reasoning occurs within the confines of pre-existing frameworks for making sense of the world and the position of the self in relation to others. Trapped in a world containing only difficult emotions and voices which are critical and confirming beliefs, increases distress and rumination. Increased preoccupation with ideas and beliefs in isolation appears to increase conviction and the experience becomes reality.

Theme Three: Experiencing Unusual Beliefs

Purpose of beliefs. Papers referencing persecutory beliefs made consistent reference to increased vigilance and focus on threat and safety as an adaptive response to current or historical situational factors, the purpose of which was to enhance feelings of safety. For some, the readiness to respond to threat made them feel stronger, more powerful and more in control. Other beliefs are also protective. Providing feelings of safety and security through wished for relationships, or more powerful identities that enabled people to transcend their negative beliefs about themselves. Others attribute unacceptable parts of themselves to

'other' entities, absolving them of feelings of guilt or responsibility due to their perceived 'badness'. Feelings of vulnerability and beliefs providing a sense of powerfulness were common themes across all papers. Beliefs enabled people to feel strong in the context of a negative self-concept, feelings of disempowerment, failure and rejection, and in anticipation of future negative or harmful interactions with others.

Positive v negative experience. Across all papers there were accounts of experiences of UBs which were at least partially valued and experiences as positive. Positive aspects of beliefs included seeing them as a gift that provided special insights or powers, special relationships and associations. Identity transforming experiences allowed people to feel special, that they have a special purpose or mission, or feel heroic, good and powerful. After crises have passed, positive experiences may continue to be valued and retained as part of the self-concept. Fear was a strong theme in negative experiences and in the context of paranoia many experienced it as constant and all-consuming and experienced frequent panic attacks. Many UBs, including those framed by religious interpretations were described as 'living in hell'. UBs drove risky behaviour in some, or led to suicidal ideation. Testing out beliefs of immortality also led to thoughts of, or actual high-risk behaviours. Positive and negative experiences within UBs are not mutually exclusive. Within challenging paranoia, there was a sense of empowerment. Within positive experiences there had been challenges with confusion, and feeling overwhelmed and afraid.

Overwhelming and out of control. The experience of UBs is described as feeling stuck, taken over, and out of control. It overwhelms to the point where the real and the unreal become blurred, or contact with reality is lost. There were several descriptions of feeling controlled by ideas, and not feeling in control of either the body or mind.

Recognising unusual qualities. In addition to feeling overwhelmed, studies also highlighted awareness that beliefs were not usual, whether it was a general sense or feeling that something was different, or awareness that what they were saying would register as unusual with others, or realisation that their experiences were not shared by others.

Theme 4: Recovering

Searching for validation. Religious beliefs often lead to seeking of validation through membership of religious organisations, while others will seek people who share similar beliefs. Validation is also sometimes sought through services. Expression of unusual ideas however is not universally welcome and can lead to rejection and further isolation. Some narratives indicate that validation is often sought in relation to experience and ideas rather than specific beliefs, as there is awareness that beliefs may not be shared by others. Awareness of difference in beliefs is sometimes experienced as harmful, increasing the sense of 'being different' in the context of a negative self-concept.

Coping. The few interviewees who spoke about medication felt it helped them gain some control over their experiences. Anxiety management skills and cognitive strategies, including challenging and reappraising of beliefs, were discussed. During recovery there was a sense that people continued making sense of what had happened, and worked hard to incorporate events into their sense of self, or 'sealed-over' the experiences and kept it separate from themselves. Others 'sealed-over' once sufficient sense had been made of events.

Making sense of experiences. In common with all phases of the experience of UBs, coping was an effortful process of making sense of complex intrapersonal experiences. As people receive 'treatment' they are introduced to competing explanations for their beliefs, including biological and psychological explanations to incorporate with their own existing

beliefs. Letting go of valued beliefs and experiences was difficult and some wished for positive aspects to remain a part of their self-concept. People held multiple, seemingly contradictory explanations for their experience incorporating biological, psychological, religious and other culturally referenced explanations, with different frameworks dominating at different times. People either move between different explanations at different times, or integrate models effectively. Others hold seemingly incongruent ideas and are ambivalent about the contradictions. Not all found multiple models helpful, and persisted with their original reasoning. Others tired of explanations cancelling each other out, so stopped trying to make sense of their experience.

Summary

Throughout analysis there was an overarching theme of effortful cognitive processing to integrate and make sense of experiences. UBs emerge in the context of difficult emotions which add emotional salience to idiosyncratic emerging theories. Reasoning was influenced by self-concept, historical experience, cultural context, personal interests and beliefs systems. Returning to a position where one could hold and integrate multiple frameworks of understanding appears to be integral to the recovery process. Valued parts of experiences and explanations may be retained; however, this does not prevent moving towards more culturally shared explanations. Awareness that others are unlikely to share or endorse beliefs was present, but having others prepared to listen to and validate experiences was important. Awareness of beliefs as unusual may also be experienced as harmful, increase inter-personal distance, and impact on self-concept.

Discussion

This synthesis reviewed 10 peer reviewed qualitative research studies in UBs in psychosis. The aim of this review was to provide an overview of qualitative inductive

research into the experience of UBs and evaluate where this may complement current understanding and inform improved clinical intervention. Accounts presented in the qualitative literature are supported by wide ranging studies that have sought to explain the precursors, onset and maintenance of UBs which are discussed alongside the four themes identified in this review.

'Reflections on cause' highlighted the role of early and stressful or traumatic life events that participants incorporated into their understanding of why they have experienced UB's. Narratives emphasised connections with difficult emotions experienced in childhood that were linked to UBs. Fear and sense of the self as bad or weak were common, while reflections on childhood beliefs, interests, and cultural contexts demonstrated thematic links to the content of many beliefs. Negative early experiences have well documented links with UBs (Dickson, et al. 2016; Read, et al. 2009), and can be understood in the context of attachment theory, which suggests attachment relationships shape the working model of the self and others (Bowlby, 1988). Early neglectful relationships are linked with a sense of the self as bad, and unlovable, that is reflected in grandiose beliefs, while hostile relationships result in a sense of the self as weak and vulnerable, reflected in accounts of persecutory delusions (Strand, et al. 2015). Evolutionary perspectives link experiences of prolonged or chronic threat to activation of physiological stress responses that can result in sensitivity to signals of social threat, affecting the ongoing social cognitive processes of mentalisation, and social rank theory, responsible for evaluation of the self in relation to others (Gilbert, 2005). This leads to increased attention to threat, increased self-focussed attention, self-attacking, and monitoring and perception of others as powerful and liable to present threat, and confers high sensitivity to rejection (Gilbert, 2005). This is supported by research that indicates neurodevelopment is shaped by early deprivation or abuse resulting in social cognitive difficulties (Bentall, Fernyhough, Morrison, Lewis, & Corcoran, 2007).

‘Evolution of beliefs’ highlighted the context in which beliefs become increasingly idiosyncratic. In conditions of chronic stress and relationship disruption, strenuous attempts are made to integrate ambiguous and globally confusing sensory, emotional, and perceptual experiences, often in social isolation, as anxiety increases. A single explanation for experiences is sought as uncertainty is undesirable and intolerable. Emotional salience leads to selection of a hypothesis that is consistent with the pre-existing negative self-concept, prompting self-criticism and self-attacking, increasing and perpetuating the emotion experienced. Underlying the well documented, jumping to conclusion bias appears to be difficulty tolerating uncertainty, with urgency reflecting a rush to resolve intolerable ambiguity, establishing certainty at the cost of a positive sense of self (Broome, et al., 2007; Corcoran et al., 2008). Narratives illustrate the high levels of anxiety experienced, and uncertainty regarding the motives of others in the experiences of paranoia, which is consistent with studies highlighting external attribution bias (Bentall, et al., 2001), and over anticipation of threat (Bentall, et al. 2008; Freeman & Garety, 2013). The dopamine hypothesis suggests that aberrant dopamine underlies cognitive processes implicated in the onset of UBs (Boyd, et al., 2017). The hyper-salience of evidence-hypothesis match, in which internal and external events are matched to internally generated hypotheses and attributed high significance, reinforcing beliefs (Broyd, et al., 2017). When faced with uncertainty, emotional salience also leads to inductive reasoning errors (Corcoran, et al. 2006; 2008), with hypothesised explanations for experience which resonate with the emotions and concepts already consistent with the self, held with more certainty than others (Broyd, et al. 2017). Metacognitive beliefs about worry drive attentional focus on concerns until a solution, or satisfactory explanation is found (Startup, et al, 2016).

‘Experiencing beliefs’ highlighted that UBs evolve to fulfil a need or purpose, and are a mix of positive and negative experiences that feel overwhelming and out of control. Often

UBs are recognised as such; however, this can impact on an already negative self-concept exacerbating isolation. Experiential avoidance associated with low self-esteem further UBs (Udachina, et al., 2014) and is consistent with the UBs as a defence hypothesis in which individuals seek to protect themselves from perceived harm and further erosion of self-esteem (Bentall, et al., 1994). There is a sense that UBs are held with increasing conviction, reflected in the shift from figurative to literal explanations of experiences, which are influenced by pre-exiting belief systems and cultural context, consistent with Maher's (1988) model explanations sought for unusual experiences will draw upon existing frameworks of understanding and beliefs. Further mechanisms by which UBs evolve and are sustained are mooted by Gurin and Blum (2017) who suggest a neurocognitive hypothesis of UBs, with functioning influenced by disrupted neurotransmitters, which affects cognitive processing in the right hemisphere. Consequently, the right hemisphere is unable to mediate perceptual integration, monitor attentional processes, detect abnormality, or update beliefs while experiencing psychosis (Gurin & Blum, 2017).

'Recovering' highlights the social process of searching for validation, and coping with cognitive and emotional aspects of beliefs, followed by attempts to make sense of experiences through a process of integration of both multiple frameworks of understanding, and integration of experiences into self-concept. These are not universal processes however, with others maintaining a single framework to explain beliefs, and others 'seal-over' experiences to facilitate moving forward with their lives (Larsen, 2004). Though often experienced as overwhelming and out of control, there is hope in recovery. For many, positive aspects of experiences can be identified, and consistent with the qualitative studies, experiences are valued with some belief content being thought of as a helpful and unique gift (Anderson, 2014; Strand, et al., 2015).

Strengths and Limitations

This review followed PRISMA guidelines for the production of reviews (Moher, et al., 2015) and followed robust transparent methodology (Thomas & Harden, 2008) using an inductive approach to translate findings across studies. While qualitative reviews are often criticised for decontextualizing findings, individual study details are presented to enable the reader to interpret findings in the context of the original papers.

A limited number of papers were available for this review and reflect a broadly westernised experience, limiting cultural generalizability. Quality assessment revealed challenges with methodology, procedure and transparency of data analysis, however findings of lower quality papers were broadly consistent with others, increasing confidence in the interpretations. Authors findings were scrutinised in the context of the first-person quotations for consistency to overcome these limitations. Limiting inclusion to inductive peer reviewed literature excluded alternative methodologies and grey literature, which may have contributed additional perspectives and themes, however, contributed a sufficiently varied range of perspectives for the purposes of this review.

Future Research

First person qualitative accounts add a unique and important perspective, offering insights not available in qualitative data, however, in common with wider research fields, literature reflects limited cultural diversity in experiential accounts. Further investigation of those who successfully negotiate living in both the world of their UBs and the culturally shared world, and function well, could inform future clinical intervention if elicited in more detail. Views of clinicians, particularly those who find UBs challenging or distressing to work with, may reveal new insights about processes involved in treatment of UBs.

Framework analysis based on extant quantitative theories, and incorporating a wider range of methodologies, may reveal new insights into the processes underlying UBs.

Clinical Implications

Critical insights are elicited in these first-person accounts. Firstly, in the search for validation, refusal to discuss beliefs is experienced as harmful, exacerbating isolation. There is little evidence that others expect beliefs to be endorsed, however there is a need for experiences to be heard and validated. Invalidation is experienced as rejection, reinforces awareness of the self as different, and increases distance from others, and leads to reluctance to engage with services. Secondly, a critical process in the evolution of UBs is the intolerance of emotion and uncertainty. This suggests interventions aimed at increasing emotion tolerance and cognitive flexibility may be mechanisms by which tolerance of uncertainty could be improved, enabling people to hold multiple hypotheses, indicates as a critical step in recovery. Third wave approaches such as compassion focused and acceptance and commitment therapy, incorporating mindfulness approaches may be beneficial.

Also of note, the optimum process of recovery does not involve the replacement of one set of beliefs with another, but an integration of frameworks that allows retention of valued and helpful parts of experiences, and integration of experiences into self-concept, which suggests that introducing medical or psychological clinical frameworks may be more acceptable if framed as an alternative potential hypothesis for experiences, as opposed to an objective fact.

Conclusions

Findings suggest that experiencing UBs is an understandable response to a complex, emotional and confusing experience, and an experience that is often at least partly valued. There is potential for clinicians to be harmful as well as helpful in responding to UBs,

particularly through invalidation of experiences. Intervention approaches should be reflexive and attend to emotional difficulties and restoring cognitive flexibility and tolerance of uncertainty.

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Chapter 2

Carers' Experiences of Unusual Beliefs: An exploration of acceptance and burden

Abstract

Unusual beliefs are experienced in the context of several psychiatric diagnoses, and cause significant stress and burden for informal carers. Outcomes for carers are variable, suggesting differences in adjustment. Taking a symptom based approach, experiences of unusual beliefs were explored with fifteen family carers. Interviews were conducted and analysed using a grounded theory methodology and a model was developed to explain differences in carers' adjustment to unusual beliefs. Results indicate that some carers adjust well and achieve acceptance of unusual beliefs, which improves their perception of coping. High motivation, influenced by relationship attachment and caring values facilitated positive adjustment and acceptance by developing a psychosocial understanding of beliefs. A negative relationship history and an absence of family or social support in the context of overwhelming stressors was associated with low acceptance and poor outcomes. The results are discussed in the context of attachment literature which provides a framework for understanding differences in carers' motivation.

Introduction

There are an estimated 6 million informal carers in the UK (Carers UK, 2011), many of whom experience caring as a burden, with negative consequences (Connell, Janevic, & Gallant, 2001). However, they play a critical role in achieving positive outcomes (Amaresha & Venkatasubramanian, 2012). Two diagnoses, 'schizophrenia' and 'dementia', are regarded as chronic health conditions (D'Alton, Hunter, Whitehouse, Brayne, & George, 2014; Lee et al., 2013) requiring ongoing support, the responsibility for which often falls on family members (Brodaty & Donkin, 2009). Prevalence of 'schizophrenia' is estimated at 0.4% (Saha, Chant, Welham, & McGrath, 2005). 850,000 people in the UK were estimated to have

dementia in 2015, a figure which is increasing in line with the ageing population (Alzheimer's Society, 2014). These diagnoses are frequently associated with unusual beliefs (UBs), which are synonymous with 'delusions' as described in the DSM-V (American Psychiatric Association, 2013). UBs are very common in psychosis, and prevalence in dementia is estimated to be 20% to 32% (Migliorelli et al., 1995; Fernández, Gobartt, & Balañá, 2010).

Caregiving for people with dementia is associated with poor physical and psychological health (Vitaliano, Zhang, & Scanlan, 2003), particularly for spouse carers, but also the wider family, and in the presence of additional contextual stressors (Connell et al., 2001). UBs cause a significant additional burden, negatively impacting on carer wellbeing (Fauth & Gibbons, 2014; Kaufer et al., 1998). Caring is similarly challenging in the context of psychosis, causing high emotional and physical burden (Perlick et al., 2006; Reed, 2008). Relationship to the care recipient, education levels, frequency of acute episodes and negative subjective appraisals are thought to influence the process of caring. (Gutiérrez-Maldonado, Caqueo-Urízar, & Kavanagh, 2005; Jansen et al., 2015). UBs also effect carers disproportionately in psychosis, impacting on wellbeing, distress and burden (Onwumere, Learmonth, and Kuipers, 2016). Carers struggle to understand UBs, fear UB related behaviour, hide the difficulties they face, and learn how to cope with and respond to UBs experientially (Onwumere, et al., 2016).

Despite the challenges, some carers experience positive outcomes. Positive outcomes are associated with a problem-solving coping style, high social support, optimism, high levels of self-care, high self-efficacy beliefs and being able to take an alternative perspective on situations (Connell, et al., 2001; Crellin, Orrell, McDermot, & Charlesworth, 2014). Although carers for people with both dementia and psychosis experience burden exacerbated by UBs, studies suggest attributions for responsibility and control over UBs may be different,

specifically that they may be higher in the context of psychosis (McNab, Haslam, & Burnett, 2007), and lower in the context of dementia (Samuelsson, Annerstedt, Elmståhl, Samuelsson, & Grafström, 2001).

Negative outcomes are associated with high expressed emotion (EE) in both psychosis (Raune, Kuipers, & Bebbington, 2004), and dementia (Vitaliano, Young, Russo, Romano, & Magana-Amato, 1993; McNab, et al., 2007), resulting in perception of higher burden (Finnegan et al., 2014; Jansen, Gleeson, & Cotton, 2015; Crellin et al., 2014). High EE at onset however, is thought to be an adaptive attachment response to loss (Patterson. Birchwood, & Cochrane, 2005). EE remains high, with high coercive criticism, for the duration of untreated symptoms, but resolves to low EE in some relationships (Patterson, et al., 2005). Low EE caring is typified by high empathy and compassion, and is associated with a sense of acceptance that reduces perception of burden (Dorian, Garcia, López, & Hernández, 2008; Shim, Barroso, & Davis, 2002). Dorian, et al., (2008) suggest low EE carers are more likely to exhibit "global acceptance" of circumstances, suggesting acceptance is a positive paradigm for understanding family roles and outcomes.

Despite being cited widely as presenting the greatest challenges in quantitative literature, the experience of carers coping with UBs is not well understood. This study explored experiences of UBs with the aim of identifying acceptance, defined as the ability to acknowledge and turn towards reality, even when painful or difficult, without engaging in attempts to change that reality (Fletcher & Hayes 2005). Exploring UBs in the context of acceptance highlights differences in carers' approaches, and the role of attachment and values in shaping motivation and outcome.

Research Aims

The overall aim of this research was to develop our understanding of the role of acceptance with regard to carer burden, and develop a model of the factors that contribute to the acceptance of unusual beliefs.

More specific research aims include exploring:

- the family caregivers' experience of UBs in the context of psychosis and dementia;
- the relationship between increased burden and unusual beliefs;
- the relationship between acceptance and burden;
- carers' coping strategies and adjustment to unusual beliefs;
- acceptance of unusual beliefs and, if achieved, identifying the underlying factors that enable a carer to successfully adjust to and accept unusual beliefs.

Method

Research Design

This study aimed to explore carers' experiences of UBs. While there is a rich body of literature on carer experiences a search revealed there were no prior qualitative studies into carers experiences of UBs. The aim was to generate theoretical understanding of how they make sense of, and adjust to UBs. As grounded theory approaches examine experiences within a purposively sampled population to create a theoretical model to account for social processes it was identified as the methodology most suited to achieving these aims. This methodology benefits from robust and transparent analytical procedures, overcoming criticisms of subjectivity applied to many qualitative methodologies. Grounded theory enables the construction of a model of processes to indicate the factors that account for variations. Such models enable enhanced confidence in identifying and targeting interventions (Glaser, 1998, p. 5.).

Epistemological Stance

Grounded theory is a qualitative methodology developed with the aim of discovering theory through a robust analytic process that allows concepts to emerge from the data gathered on the social processes undergoing exploration (Glaser and Strauss, 1967). Subsequent researchers have suggested that placing the researcher as an independent observer who can discover a theory, which is present and detectible, in the experience of participants, defines it as a positivist approach. The implication that there is a single truth to be discovered has received much criticism by other researchers, for example, Charmaz (1983) has argued that both the researcher and the participant, together with their assumptions and experiences, are intrinsic in the process, and the outcome of grounded theory methodology is socially constructed meaning of experience processed through the interaction and understanding of the participant and researcher, resulting in a 'co-construction' rather than a single truth.

To address some of the criticisms of grounded theory, Strauss and Corbin (1998) suggested that their grounded theory approach incorporates rigorous procedures that should eliminate the assumptions and preconceptions of the researcher and that selecting from a range of tools for analysis incorporates checks, balances and procedures to ensure the emerging theory is 'valid' and trustworthy. While retaining roots in the positivist stance of the original grounded theory approach, Corbin and Strauss (2008) went some way to acknowledge that the final theory will always include an element of co-construction.

The researcher herself takes a constructionist position, believing the theory that emerges is a composition of both the researcher's and participants' meaning, interpretations, actions, and interactions shaped by their own experiences, knowledge and cultural context, resulting in a co-construction of the meaning in experiential social processes. Despite holding this position, as a novice in the field of qualitative research, and having personal

experience related to the subject of exploration (see appendix F), the prescriptive processes and tools outlined by Corbin and Strauss (2008) were utilised to provide guidance and transparency through the process of analysis as qualitative research skills were developed.

Both positivist and constructionist versions of grounded theory require variation in initial sampling of participants, followed by theoretical sampling in the later stages of recruitment. Consequently, utilising Corbin and Strauss' (2008) methodology had little impact on the recruitment and sampling strategy. Straus and Corbin suggest a third stage of recruitment, in which the emerging theory and models are explored with participants to ascertain whether the outcomes resonate with participants lived experiences, adding confidence to the findings. This additional stage of recruitment was adopted in the current study.

Both Charmaz (2003) and Corbin and Strauss (2008) suggest a broadly similar two-stage process to analysis. The first phase involves coding to develop a taxonomy of categories and sub-categories, followed by a second phase of analysis to explore the relationships between those categories and sub-categories to develop a dynamic theory. While both approaches share these objectives, Corbin and Strauss (2008) provide a more structured and prescribed process of analysis at this second stage. Corbin and Strauss (2008) also suggest a third stage of analysis that corresponds with the third phase of recruitment. The aim of this final stage of analysis is to explore the emerging theory with participants, in a process of refining of the model. Consistent with the approach taken, this third phase of recruitment and analysis was also adopted in this study.

The constructivist position means that data is analysed with a particular focus on exploring the meaning of what is conveyed, and developing understanding of symbolic interactions, to ultimately achieve a co-constructed meaning of experiences. This perspective

and approach is not precluded by using the tools and methodology of Corbin and Strauss (2008), when they are adopted for the purposes of ensuring rigour and transparency in the process of analysis. Strauss and Corbin (1998) suggested that the rigorous processes are sufficient to eliminate subjectivity from the research, whereas Charmaz (2003) suggests that subjectivity can better be controlled for through explicit expression and documentation in a reflexive statement. The researcher agrees with Charmaz's (2003) view and adopted this approach (see appendix F) to ensure that this study could identify and eliminate any potentially 'planted' concepts, or over interpreted data.

Ethical Approval

This study was sponsored by the University of Liverpool. Ethical approval was granted through the Integrated Research Application System (IRAS) in March 2016 (Appendix G). Formal confirmation of the Local NHS Trust's support was obtained from the Research and Development department in April 2016.

Ethical considerations

This study involved in-depth interviews about difficult, and sometimes distressing experiences. The researcher was explicit about the nature and purpose of the interview prior to confirming continuing consent at the time of interview. Participants were debriefed at the end of the interview and provided with information about sources of support.

Close engagement with the data was required throughout the research process. Interviews were often challenging and involved distressing content. Additional supervision was sought during data analysis and a reflective diary was kept throughout.

Experts by Experience Involvement

To ensure carer perspectives were reflected a small focus group was recruited from the local University and NHS Trust service-user forums. Their feedback shaped the study design, aims, and initial interview schedule. Two pilot interviews were conducted prior to

commencement of the study to facilitate feedback and ensure the questions facilitated data collection in line with the aims of the study. The revised interview schedule was subsequently reviewed and further refined by the service-user group. Their contributions were invited throughout the study, however their circumstances precluded continued involvement.

Recruitment

Participants were recruited from community teams providing mental health, early intervention, and memory clinic services in the local NHS Trust. Study information was disseminated to clinicians and posters were displayed in local service waiting areas. Clinicians were supported by team managers and the researcher to identify and contact potential participants for the study. While clinicians identified participants according to suggested diagnoses types of psychosis and dementia, these broad categories were selected to facilitate incorporation of a range of experiences including diagnoses such as schizophrenia, schizoaffective disorder, bipolar affective disorder and delusional disorder, and a variation in dementia types, including Alzheimer's, vascular dementia and Parkinson's dementia. This was to ensure that while giving some direction to clinicians supporting recruitment, the study was able to take a symptomatic, rather than diagnostic approach. Carers implicitly defined UBs in their narrative accounts, referring to periods when there had been a divergence between the beliefs of the carer and the beliefs of the person experiencing UBs, and a change from previously held widely shared beliefs, that had caused a difficulty in their relationship, or with the cared for person's behaviour.

Study packs were mailed by the researcher to carers who initiated contact following sight of a poster. Study packs comprised a letter outlining the research purpose (Appendix H), participant information sheet (Appendix I), consent form (Appendix J) and demographic questionnaire (Appendix K).

Demographic information was used to select participants with different characteristics and facilitate exploration of emerging hypotheses (Appendix L). Information sheets and consent forms were reviewed at the time of interview to ensure continuing consent and provide the opportunity to ask questions. Recruitment took place between April 2016 and October 2017.

Participants

All 15 participants were adult family carers of people experiencing unusual beliefs in the context of psychosis or dementia. All had experienced caring in the context of unusual beliefs for a period longer than 6 months. As the process of adjustment was of interest, it was considered that 6 months would be the minimum period that would permit a post-onset reflective period, during which learning and adjustment could occur. There was no upper limit to the period of caregiving and seven of the 15 carers interviewed had been caring for a period of over 5 years. Two carers gave retrospective accounts of caring for people who are now deceased, and 13 were currently caring for, or supporting a person with UBs.

Sampling

There were three phases of recruitment, as recommended by Strauss and Corbin (2008) to facilitate open, axial and selective coding, described below. The first phase of recruitment generated eight participants. Three participants selected for interview were caring for working age adults, and three for older adults. Four participants were caring in the context of a psychosis related diagnosis. Two carers were supporting a relative with dementia.

The second and third phases used a purposive sampling method with clinicians supported to identify participants with specific characteristics to facilitate hypothesis testing, to strengthen and refine the developing model. Phase two included three carers with experience of caring in the context of dementia, and three in the context of psychosis. Phase

three included one participant caring in the context of dementia, and two with experience of caring in the context of psychosis.

Procedure

Participants completed a demographic questionnaire during the recruitment process to ensure heterogeneity of sample, and ensure factors identified in extant studies, including relationship to the carer; gender; duration of caring; income and education level could be considered in phase one (Gutiérrez-Maldonado, et al., 2005; Jansen et al., 2015; Connell et al., 2001).

To enable a broad exploration of factors, the initial interview schedule (Appendix M) allowed for a diverse sample of carers to speak freely about their experiences, including the background and context of their caring relationship. At the end of phase one a hypothesis driven revised interview schedule (Appendix N) explored the impact of UBs on the carer and relational processes more closely. The third, confirmatory phase explored the links within the hypothesised models to ensure they represented carers' experiences.

Interviews from 40 to 120 minutes in length were audio recorded and a £10 gift voucher was given to participants as compensation for their time. Five interviews were transcribed by the researcher, with the remaining transcribed by the University transcription service.

Data analysis

Grounded theory data analysis uses constant comparison to identify patterns in emerging data with a view to generating theory (Corbin & Strauss, 2008). Data was explored with the objective of identifying acceptance, and associated processes within the carer experience. Analysis of data was concurrent with data collection, following the procedure set out by Corbin & Strauss (2008). Corbin & Strauss (2008) describe a three-stage process that broadly corresponded with the three phases of data collection. The initial six transcripts were analysed using open coding, which opens up the data, coding line by line

to facilitate the emerging concepts grounded in the data. A narrative summary of each interview was documented and hypotheses were developed to account for the links in each process model, to be confirmed or refuted in subsequent interviews. Model development, coding and analysis, were carried out as parallel processes in the context of constant comparison ensuring consistency in coding. A final coding hierarchy emerged following analysis of the interview with participant 6 (Appendix O). Initially coding followed a manual process to facilitate constant comparison, while continued analysis and hierarchy development was facilitated by NVivo 10 software.

When no new information pertinent to UBs emerged in response to interview questions, theoretical saturation was discussed and agreed with supervisors. Process models, narrative summaries, hypotheses and coded data were explored to suggest hypothetical links between emerging concepts to facilitate axial coding. This culminated in preliminary models (Appendix P) and preparation of the hypothesis led interview schedule for phase two (Appendix N).

The phase two interview schedule explored processes underlying the adjustment to, and acceptance of, unusual beliefs. The second phase was analysed using axial coding and selective coding to confirm links between concepts, and identify the concepts that related closely to the emerging core concepts, while ensuring the emerging model retained fidelity to the underlying data (Appendix Q). A storyline memo was developed (Appendix R) to reflect the key research findings and a composite model was developed to account for factors underlying acceptance (figure 2).

Reflective practice and recording of memos allowed examination of preconceptions and their potential influence on interpretation of data to be robustly explored during supervision. The researcher's experiences, perspectives and expectations were recorded prior

to commencement of data collection (Appendix F) allowing for later reflection on the role of the self in the interpretation of data.

Model confirmation

An essential criteria of grounded theory research involves checking that the process has resulted in a model that fits with participants' experiences, is relevant, workable and modifiable (Glaser & Strauss, 1967), incorporated in phase three of the study (Corbin & Strauss, 2008). Three carers were recruited to the study to explore whether their experiences were represented within the model, and each was encouraged to critique the model and explore whether aspects of their experience were not represented. The participants located themselves within different pathways in the model, and they confirmed that the model was helpful in explaining their experience of caring. One carer could locate different family members in different locations on the model and developed new insights into the challenges other family members had experienced in adjusting to UBs. This carer felt the model was not only a good representation of the experience relating to UBs but could be broadly generalised to the wider caring experience. This suggests that the model may be a good fit for a range of experiences, and demonstrates utility in eliciting new perspectives. None of the carers interviewed suggested that the model required modification. The results of the data analysis are reported below.

Results

The process of analysis led to a model to account for variability in outcomes, reproduced below in figure 2, supported by the storyline memo (Appendix Q), which summarises the key findings and overall theory in narrative form (Corbin & Strauss, 2008). The findings are presented as they relate to the model.

The Challenge of Unusual Beliefs

Carers of people experiencing UBs faced several challenges. The content of beliefs was often challenging to the carer's sense of reality, their values, the attachment relationship with the person they are caring for, and sense of identity within the relationship. Challenges to values, relationships and identity elicited the strongest emotions. James' uncharacteristic language emphasised the impact of the threat to relationship and identity, and how it undermined his caring efforts:

> "*I think on the one about you're not my husband I felt anger I really did feel annoyed... I've been doing all this… I'm not your husband, I'm f****ing… pardon my language".*

Initially carers felt compelled to correct unusual beliefs, as Marie illustrated *"I was trying to make him reason it out that it wasn't feasible".* Early strategies were ineffective, and negatively impacted on the emotion experienced by both the carer and the cared-for-person, exacerbating the sense of loss. As Karen showed this in one interaction which was upsetting for both her and her father:

> *"I said 'Dad I'd never pinch your money… that's really hurtful to me, try and look after you'… and he was quite upset".*

Mark spoke about challenging interactions with his partner:

> "*it's hard to keep your cool and hard not to raise your voice and I've shouted some nasty things at her you know sort of thing. 'For God's sake' you know and I won't repeat what I've said, but it's not me…".*

As UBs disrupted the usual process of the relationship within the dyad, they negatively impacted on the process of caring and many carers felt helpless and grieved the loss of their loved one. As Emma said:

"I began to realise that she wasn't the person that I know. She was completely different… It was almost like an alien had taken over her body, and I was in despair".

Unable to find effective strategies, and worried by the UBs, carers embarked on a course of action, influenced by their motivation, to resolve the threat they were facing, illustrated in figure 2. The outcomes are categorised by how accepting carers were of the impact of UBs on the process of caring and, or, the content of UBs, and whether they were able to engage with a constructive process of adjustment. Outcomes were grouped into 'positive', 'good', and 'poor'. Acceptance is defined as the ability to turn towards reality, even when painful of difficult, without engaging in attempts to change that reality (Fletcher and Hayes, 2005).

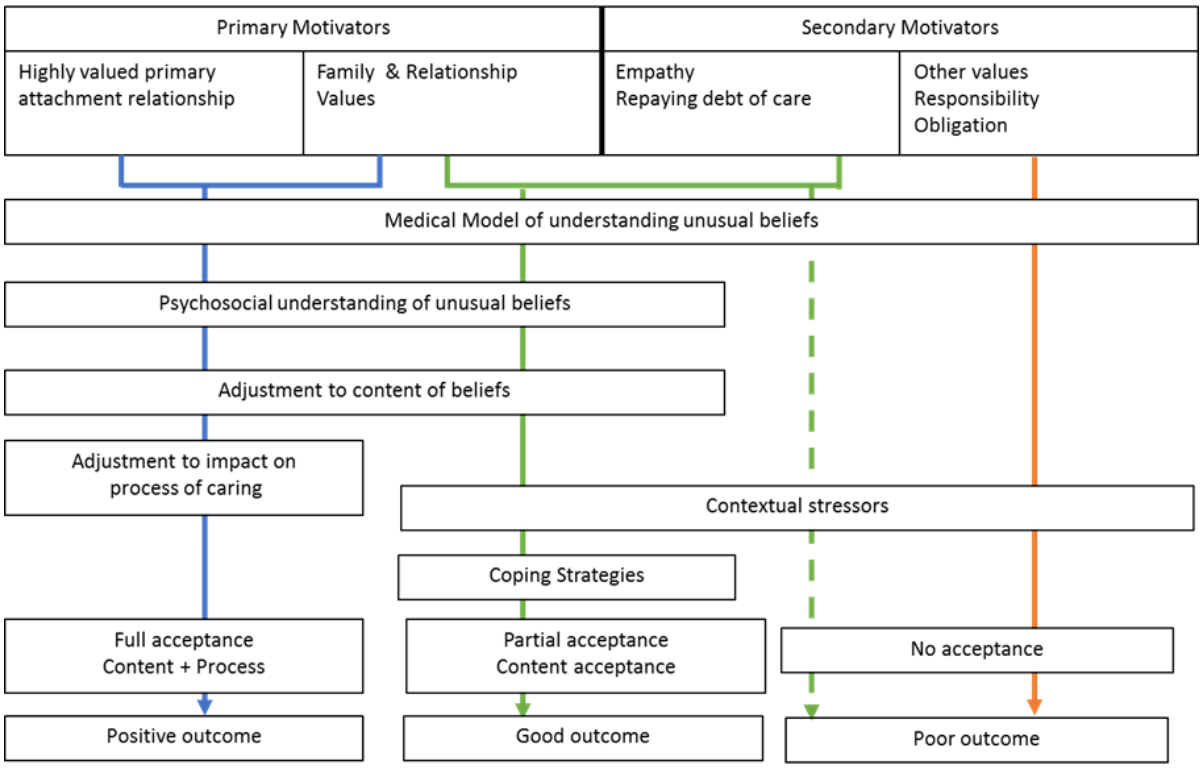

Figure 2. Model of factors influencing outcomes for carers supporting a person with UBs.

Motivation

Within this sample motivation was critical to the process of caring. Carers found motivation in a range of primary and secondary factors, however, the dominant motivators shaped the priorities of carers, actions taken, willingness or ability to adjust to, and accept UBs. Seven carers achieved a 'good' outcome, represented by the solid green line on the model. Two participants achieved a 'poor' outcome despite sharing similar motivation with carers achieving a 'good' outcome, illustrated by the dotted green line. Two participants achieved a 'positive' outcome, represented by the blue line. Two carers were facing a very 'poor' outcome, represented by the orange line. Full analysis included 12 participants in phases one and two, and a supplementary account of an additional caring relationship provided by participant 6. Representing the highest number of carers, the process will be described first in the context of 'good' outcomes.

The Pathway to a Good Outcome

Primary motivator: family and relationship values. Carers in this category reflected strong family, caring or relationship values that compelled them to care. As Laura said:

> *"to see some-one feel so lost and for me to be able to help them just an automatic thing to do… because I love her and I do want to be the best daughter I can be".*

Similarly, for Chloe:

> "*He was my brother. What else was I going to do? You know, I mean I would do that for a friend, I would do it for anybody"*.

Most had experienced a 'good enough' relationship with the person they care for, so despite the changing nature of the relationship, a strong bond was maintained. As Mark explained:

"*it's a different sort of relationship because I'm just caring for her really more than anything. It's not err, I still love her to bits… but it's not that sort of...*".

Their relationship values compelled them to seek help for the person they care for, to make sense of what is happening, and to find effective ways to help and alleviate distress caused by UBs. For example, although shocked by her daughter's presentation, Emma was highly motivated to understand what was happening:

"*I thought 'what can I do who can I turn to? Who can explain this, who can tell me?'".*

Secondary motivators: Empathy and repaying a debt of care. These carers also demonstrated a strong desire and willingness to care, which may have been driven by an emotion in the context of a historically positive reciprocal caring relationship. Marie illustrated this type of caring motivation:

"he's a good husband I mean we've had some terrible rows, but he's a good husband. I had cancer and he looked after me so well".

Most of the carers interviewed expressed feelings of empathy, for example:

"I feel more sorry for her as she is getting older" (Nicola)

"I feel for her, when her friends have got married… her life was stopped" (Emma)

"I knew he couldn't help it, I just felt really sorry" (Chloe)

Developing a Medical-Model of Understanding. During the first experience of unusual beliefs all carers sought out expert help, at which time they were likely to receive a diagnosis and develop a medicalised understanding of the difficulties, which enabled them to externalise the cause, and depersonalise the content of the belief. Marie is explicit in how her very recent acceptance of a diagnosis will change her approach:

"if he's said it now with the diagnosis I would be completely different. I wouldn't be as bad tempered, I wouldn't be as short with him"

Laura was initially upset by the content of beliefs, but became much more able to tolerate the expression of UBs "*then I think this isn't Mum, this is the brain*" and Chloe *"it was the illness and this was showing through"*. Most carers reach an acceptance of 'illness' as the source of UBs. As Marie said:

"*I remember the doctor saying to me don't argue with him, walk away… I used to say 'you're talking a load of rubbish'. How stupid when I think of the things I've said"*.

Developing a medicalised understanding confers short-term benefits, however, to cope with ongoing or recurring UBs further understanding is needed, and both motivation and opportunity are necessary to achieve this.

Developing a Psychosocial understanding of Unusual Beliefs. Carers who achieved 'good' or 'positive' outcomes spoke about wanting to understand what was happening and wanting to help. They were motivated to seek information from a variety of sources, including local services, which led to a broader understanding of UBs. Susan typified several responses about gathering information:

"*if there was anything that would help me to learn about the situation and then use it, take it away, help put my mind at rest".*

This facilitated a natural process of reflecting and formulating causes, triggers and maintaining factors, linking current and past events. Rachel talked about making sense of UBs in a psychologically informed way, and recognised the social and emotional triggers for voices and consequent paranoia:

"I know unusual beliefs, they tend to have something beneath them. There's something that's precipitated it, be it something ridiculous something small or something huge and I think the reason he heard [her] voice is because we hadn't talked to her for a long time and he had a huge battle with himself over his relationship with [her]. As in he loved her but she mistreated him".

"he was paranoid again and I was in work… his daughter came round when I wasn't there… and he'd started hearing voices because of the pressures that I wasn't there, the stress that I was in work"

Psychosocial understanding increased empathy, and naturally indicated helpful strategies or responses, facilitating adjustment and ultimately full or partial acceptance of UBs.

Adjustment to Content of Unusual Beliefs. The adjustment process started with the accommodation of the new information gathered, supplemented by experiential learning, which facilitated the formulation and development of effective strategies, reducing the emotional impact of UBs. Marie illustrated this change: "*it was hurtful when I thought he meant it and then you sort of realise".* There is often a process of rupturing and then repairing the relationship, as Mark articulated:

"later on I'll just, when she's lucid, when she knows what she's talking about sort of thing, she'll know that she's been saying things that she says I'm sorry and I say I say well I am too… I've been saying things to you that I shouldn't".

Being able to make sense of UBs that were rooted in medication side-effects changed the way Rachel responded, no longer feeling threatened by the accusations, she was able to offer support to check beliefs, and reassurance:

"He was [saying] 'I'm not a man', that that was part of he should leave me, and then that fed into I'm going to leave him, I'm going to have an affair".

Emma connected past experiences to her daughter's paranoia, so was very considered in her responses and took care not to be dismissive:

> *"bearing in mind that she has been through trauma, that things have been taken out of her control… she was a bit suspicious, and I think yeah, if you keep seeing somebody that you have not seen for a long time… I didn't want to encourage the paranoia, at the same time, she could be right…"*

Understanding that conflict and stress exacerbated UBs carers often took increased responsibility for maintaining a positive relationship, absorbing potential conflict and protecting the cared for person by concealing their feelings. A good example of this came from Laura:

> "*when she was upset last night obviously I got upset but I didn't cry I just got upset for her. I literally can detach myself, wall up and just think 'calm her down'".*

Adjusted goals. A biopsychosocial understanding of UBs changed the carers' goals, from getting rid of UBs to reducing the impact, frequency, and duration of beliefs. They prioritised meaningful engagement and enjoyment. As Laura said the priority was *"to have some memories where we're giggling and laughing".* Stress reduction becomes a primary goal, as Chloe said *"well I was trying to get stress off him".* James' goal was to minimise distress and agitation:

> *"this business of putting her coat on and wanting to go and see her Mother, or her Sister's coming… go along with it, I think it's acceptance, because I can't see anything to be gained by fighting them because they contradict you and they get argumentative and then they get agitated then you have the agitation yes… you want to keep them calm".*

Adjusted strategies. As goals change, the strategies used are adjusted. For these carers achieving goals meant soothing distress, and validating experiences and emotions. They spoke about the importance of engaging a person in meaningful activity and encouraged meaningful relationships. A range of creative and flexibly applied strategies were used by these carers to achieve their goals. Strategies used in psychosis and dementia were distinct, so are reported separately.

Strategies in dementia. To achieve their goals carers found that 'playing along' with the belief and empathising helped to minimise distress, illustrated by Karen:

> *"I think the easiest thing is just to agree and just say oh I know it's awful isn't it, I always try and cheer him up and so he'll laugh"*

Similarly, James advised:

> *" she said erm 'the other men… have they gone or are they sleeping next door', I said 'no I've just said goodbye they're alright'"* .

Distraction was a helpful strategy, which included engaging in valued activity and sensory stimulation, and often made use of autobiographical knowledge of the person. James talked about supporting his wife's wish to visit to her mother until an opportunity for distraction arose:

> *"she put her coat on and we got in the car and then on the way she couldn't remember where she was going then... well we've got to find someone who knows where we're going. By the time we got home and had a cup of tea, she started to watch the television... it was diversion tactic yes"*

Carers spoke about flexibly applied routines incorporating favoured shared activities that promote meaningful engagement. Carers referred to changing their lives and routines so

they were sharing the world of the person they were caring for. Carers also found promoting positive emotions helpful, as Karen said:

"if you can make him laugh he remembers that he's in a good mood"

Many used environmental interventions to minimise triggers for UBs, such as using visual reminders, covering mirrors, and having routine locations for keeping important objects.

Strategies in psychosis. During crises, carers felt there was little they could do to influence UBs, so focussed on empathising and reassuring. For example, David advised:

> *"you have just got to say something to try and you know, reassure her that she is not in any trouble, she didn't do anything"*.

Carers use their knowledge of the person and caring experience to gauge when further intervention may be helpful. Carers spoke about inviting dialogue about beliefs and active listening, often leading to collaboratively agreed strategies, which often incorporate supportive exploration of evidence for and against beliefs, and encouraging reflection about what had been helpful in the past. As Susan explained *"I try collaboratively to use previous experience because she has come through it before".* Many carers could tolerate UBs, while presenting their own beliefs as different, for example Emma:

> *"It's not that much different, if someone talks to you that it's a flat earth… you'd talk to them wouldn't you, and you say here's the facts as I see them, you see something different, tell me what you see and why you think that, so it's a bit like that".*

Contextual Stressors. Many carers spoke about additional contextual stressors, including role conflict like Laura, "*I'm putting her before everybody and I feel so much guilt to my children"*, worry about recurrence or worsening of UBs, and risk, as Emma explained how difficult crises can be:

"I don't know what's happened, I don't know where she is, whether she has committed suicide"

For carers of people with dementia a very significant stressor is long term sleep disruption:

"it's stress, it's really stressful you know and the lack of sleep doesn't help it at all." (Mark)

Coping Strategies and Support. The impact of stressors was moderated by a range of coping strategies which often include self-care activities, maintaining supportive relationships with family, friends and services, and maintaining other valued roles.

Partial Acceptance - Acceptance of content. Carers who were motivated by caring values accepted the content of beliefs, for example Laura:

"I think that's important to someone who has these beliefs, there's no right and there's no wrong in that moment they are the only right"

They find burden and stress reduced as a result. As Chloe states

"*People behave like they behave, they're not doing it on purpose so you have to accept it and get on with it, I just accepted it, I'm one of those that just takes thing takes things as they are"*

Good Outcome. A 'good' outcome was associated with confident coping and reflected a shift in thinking. As Karen commented:

"I thought oh I'm never going to cope it's going to be awful and everything's just going to get worse but I don't think like that anymore"

Acceptance of the content of beliefs was subjectively related to 'coping well' and lower burden.

The Pathway to a Positive Outcome

In common with the 'good' outcome group, carers on the pathway to a positive outcome shared the motivation to seek out and develop a psychosocial understanding of UBs, which facilitated adjustment and acceptance of the content of beliefs. The two carers experiencing a 'positive' outcome however shared characteristics not shared with the 'good' outcome group. Both were spousal carers in highly valued relationships. This generated additional motivation that facilitated adjustment to the process of caring.

Primary motivator - Highly valued attachment relationship. These two carers shared a level of relationship commitment not represented in parent/child or sibling dyads, and experienced a profound sense of relationship loss as a consequence of UBs. Their motivation was to maintain and restore the relationship, illustrated below:

> *"I just felt, I just had to be there for him… I don't know how I got through it I think just determination that I wasn't going to leave him, I was going to be there for him" (Rachel)*

> *"They say 'aren't you wonderful, caring', but I never looked at it that way, it's what I signed up for" (James)*

Adjustment to Impact on the Process of Caring. These carers prioritised maintaining a harmonious connection within a highly compassionate relationship. Their primary goal was to protect the relationship. They could tolerate and absorb conflict to minimise relationship stress, while the content of beliefs was often ignored, as Rachel explained:

"I felt like I could defend myself if we were in an argument, but when he was unwell, no I just backed down every time and still to this day do".

Adjusted Goals. To protect their relationships, both carers made a significant effort to maintain their role as a trusted person, and focussed on creating a dynamic that enabled the person to feel safe. Rachel, who fought to prevent hospital admissions, was extraordinarily accepting and protective through crises, commented:

"I think he respects that I was there for him":

> *"I've not challenged him, I've been backed down completely… I literally bite my tongue at times and I'll just say nothing, and if it's upset me, I just take myself off and when I come back he'll be paranoid, I'll just say I've been putting the washing away, redo my makeup so he doesn't know I've been crying, if he sees I've been upset he then feels really guilty and that doesn't help with his beliefs. He then goes into a spiral so I just hide everything."*

Full Acceptance - Acceptance of process. These carers appeared to have exceptional acceptance of the impact of UBs, for example James demonstrated global acceptance of change: *"I think because you accept it, I accepted this is what's life is going to be",* and allowed himself to be led by his partners' needs:

> *"So what I found actually was that if she went to bed at 9 o'clock I too went to bed at 9 o'clock… the routine was structured from whatever time she happened to get up into the routine, you know get her dressed into the lounge, cup of tea, then probably if it was 3 o'clock in the morning a piece of toast"*

They were also able to see value in their experiences, illustrated by Rachel

"it's still hard you know but it has changed life completely, our lives are completely different to how they were before, it's given us more respect of life for both of us".

Positive Outcome. Both carers provided very caring environments which protected their spouses from extraneous responsibility, conflict and stress. They both framed difficulties as temporary, fostering hope, which facilitated ongoing coping. James illustrated this when reflected on loss of social relationships and hobbies that was of little concern *"I knew I could always get back to it".* They shared an optimistic outlook, and made little reference to contextual stressors being problematic.

Despite their resilience however, these carers seemed to strive to give perfect care, subjugating their own needs to preserve the relationship, which may confer some risk to the caregiver during any perceived failures in caregiving. Positive outcomes were not related to sex of carer or diagnosis.

The Pathways to a Poor Outcome

Four carers, who appeared to fall into two groups, were not able to develop psychosocial understanding of beliefs, and did not adjust, which appeared to prevent acceptance of UBs. Both groups showed low adjustment but were differentiated by their motivation which influenced the acceptability of the carer role.

Limited to a medicalised understanding, these carers were left relying on 'expert' help and feeling powerless and helpless. David reflected that *"the last few weeks has changed with a change in medication"* and suggested 'experts' are better placed to offer support *"Well they're used to talking to people with these problems, it's their jobs".* This was especially evident for long term carers in the context of psychosis, for example Nicola commented:

"I have a feeling of helplessness… occasionally I have rung the psychiatrist. You know you're pretty helpless really".

Consistent with the medical model, recovery was thought of as restoration to the previous self, an often-unattainable goal, leading to increased feelings of loss, failure and helplessness.

High Motivation, Low Adjustment. Represented by the dotted green line in the model, these two carers demonstrated a high commitment to caring, and acceptance of the carer role, but difficulty accepting UBs. Developing a psychosocial understanding required both motivation and opportunity. A high number of contextual stressors, low social support, and delayed diagnosis reduced opportunity to access services and information that facilitated adjustment, and reduced cognitive resources required for processing new information. For example, Mark:

> *"for months… I don't think she has slept all the way through the night without waking up and saying things, I'm on edge … I'm all night on call… if I could get sleep I could cope with all of it, when you're tired it's bloody hard".*

Low adjustment to UBs led to low acceptance, as Marie said, *"I can't understand how he cannot logically think I wouldn't do that".* Having only received a diagnosis on the day of the interview, Marie was only just beginning to understand that 'illness' was causing UBs, and did not feel that she would be able to accept them:

> *"I couldn't say I could accept them, I can understand**,** he doesn't really know it's in his head, he firmly does believe what he's saying and I can understand that he believes what he's saying but I would never accept it"*

Nevertheless, despite the challenges, both demonstrated a high commitment to caregiving:

> *(Marie) "its very important that I maintain all my relationship with him very very important. He is now my life"*

(Mark) "I just try to, I just know it's got to be… I've got to just keep trying, you know to help her"

Low Motivation, Low Adjustment. Represented by the orange pathway in figure 2, two carers with a challenging relationship history with the cared-for-person, were motivated to care by a sense of obligation, or cultural expectations. The values expressed by these carers, for example, autonomy, achievement, novelty in experiences and challenges, may also conflict with caring values. Although some caring values were evident and expressed towards others, these were not dominant, and prior relationship difficulties prevented expression of warmth or empathy towards the cared-for person. Blame, and a sense of anger, frustration or resentment were apparent. Here is an example from Karen, who reflected on the challenges of family carers:

"Dad had a really bad drinking problem when he was at work, I think a lot of people that work in those kinds of jobs do and [she] sort of blames that for his dementia"

Nicola expressed resentment at the loss of her planned future with her husband:

"She is very close to my husband, very very close… It has definitely affected our relationships"

Duration of the period of caregiving, in the context of low motivation, also appeared to influence outcome. Nicola, caring for over two decades, shared her diminishing optimism, commenting: *"it feels less hopeful"*. Few positive interactions were reported with services, and intervention was often rejected, derided or perceived as unhelpful. Suggested strategies were not seen as credible therefore not implemented willingly, and loss was predominantly self-focussed.

No Acceptance. Carers in the low adjustment groups found it difficult to accept any aspect of UBs and relied on passive hope for change, illustrated by continued use of ineffective strategies, which caused ongoing frustration:

> *"I can't change that, you know I can't make her see that, you know, what I'm saying to her…"(Mark)*

> *"I'm finding it hard to accept that he's got this brain disorder as severely as it is… eventually I will come to accept this and then I will deal with it" (Marie)*

Although Nicola talked about acceptance, the narrative suggested that this was more akin to 'resignation' than acceptance, illustrated by the following exchange:

> *Interviewer: When you mentioned accepting things as they are, I am wondering if that feels like a positive thing?*

> *Nicola: No*

> *Interviewer: Has it ever felt acceptable to you?*

> *Nicola: I don't think you can not accept it because it is the hand that you have been dealt and you have got to accept it. You have got to put up with it, you can't change what has happened. Much as you would like to.*

Poor Outcome. Poor outcomes are associated with high stress and high perception of burden. Most challenging for both the cared-for person and the carer is an absence of primary motivating factors.

The low motivation relationships confer risk for the carer, particularly those co-habiting. Feeling trapped, resentful, angry, depressed and hopeless, there is a strong desire for the situation to end. As Karen reported:

"she's saying 'I'm 80, is this all I've got to look forward to the rest of my life?'"

Carers may see the end of life as the only way out, as Nicola concluded:

"It can't improve. It feels horrendous, horrifying, is this all there is to life? I joke about 3 single tickets to the Dignitas clinic".

Summary

Not all carers found UBs the most difficult aspect of caring, with two thirds of carers citing additional complex health needs, family conflict, role conflict, risk, and sleep deprivation as more difficult to cope with than UBs. All carers expressed that caring was challenging and stressful, however the degree to which carers were impacted by stress varied considerably. Most carers had multiple primary and secondary motivators that compelled them to take on the carer role, and while they may not have fallen exclusively within one category, participants indicated their dominant motivations, which influenced the trajectory of their caring experiences. Carers who had a positive relationship history with the cared for person, and had strong caring values showed motivation to seek information and make effortful adjustment. They discovered a range of successful interventions, were accepting of the carer role, changes in the relationship and the person. They viewed their coping positively and were more accepting of UBs.

Low access to information, due to either high contextual stressors or low motivation, led to low adjustment, high stress, continuing difficult interactions, low acceptance, poor perception of coping and high perception of stress and burden. Caring in the context of a poor or abusive relationship history and low relationship and caring values, possibly a consequence of the carer's own difficult attachment history, was particularly problematic. Negative attributions and relationship patterns continued to play out in the context of increased vulnerability. The carer role was not acceptable and it seemed unlikely that such

relationship dyads could support an appropriate caring environment for either the carer or the cared-for-person.

Discussion

The objective of this study was to explore carers' experiences of supporting a person with UBs in the context of psychosis or dementia, and the relationship between UBs, burden, and acceptance. The aim was to develop a model that accounts for the factors that contribute to the acceptance of UBs and their influence on outcomes.

Increased carer burden was found to be associated with UBs, however many carers cited stressors that were more challenging to cope with. Four types of carers were identified, who were differentiated by their primary motivation for caring, which accounted for variability in acceptance and outcome.

Onset of UBs presented a challenge for all carers. Carers experienced shock, distress and a sense of failure, and loss, particularly when their values and relationships were challenged. Carers instinctively made attempts to correct the beliefs, increasing conflict and distress experienced by both the carer and cared-for-person. Carers struggled to make sense of beliefs and experienced high burden and stress during the initial crisis. Unable to correct UBs, carers sought professional help. Diagnosis led to a medical-model of understanding, and acceptance that UBs were caused by illness. This facilitated and externalising of belief and depersonalisation of content. This brought some short-term relief however was insufficient to facilitate adjustment and positive ongoing caring. Carers who had insufficient resources or motivation remain stuck in a cycle of negative challenging interactions, with long term consequences for their wellbeing. Primary motivating factors drove a search for information that led to a deeper psychosocial understanding of UBs that facilitated formulation, adjustment of goals and strategies, and acceptance.

Consistent with existing literature, carers experienced negative consequences of UBs (Connell, et al., 2001) including increased burden, relationship conflict and distress, and struggled to make sense of beliefs (Burns, 2000; Fauth & Gibbons, 2014; Kaufer et al., 1998; Onwumere, et al., 2016; Perlick et al., 2006) during initial crises. As Patterson, et al., (2005) suggested, interactions during initial crises reflect a response to threat, which is adaptive in the context of attachment literature, and early carer strategies reflect the coercive criticism element of high EE, which declines as challenges are resolved (Patterson, et al., 2005) as carers adjust. Also, consistent with previous research, for carers who are unable to adjust, unresolved difficulties lead to continuing high EE, increasing perception of burden and stress (McNab, et al., 2007; Raune, et al., 2004). Carers in the high motivation, low adjustment group gave accounts of caring in line with studies that suggest that a high burden of care and low social support impact on health and wellbeing and negatively influence outcomes (Connell, et al., 2001; Jansen et al., 2015; Reed, 2008; Vitaliano, et al., 2003).

The narratives of the 'low motivation' carers resonated with the current literature EE that suggests high EE carers are involved in ongoing negative interactions. High EE caregiving is associated with poor outcomes for both the carers and the cared-for-person (McNab, et al., 2007; Raune, et al., 2004; Vitaliano, et al., 1993) and a high perception of burden in carers (Crellin et al., 2014; Finnegan et al., 2014; Jansen, et al., 2015).

The carers who achieved good or positive outcomes showed high motivation to find information to help them solve problems faced, and ability to accommodate new information and skill in formulating and generating appropriate strategies. Stressors were balanced by self-care and engaging the support of others. Those in the 'positive' outcome group were also able to demonstrate flexibility in reframing difficulty as temporary. This is consistent with literature pertaining to the broader caring experience that associates positive coping with problem-solving approaches, high social support, optimism, high levels of self-care, high

self-efficacy beliefs and being able to take an alternative perspective on situations (Connell, et al., 2001; Crellin, et al., 2014; Samuelsson et al., 2001). During adjustment, the 'positive' and 'good' outcome groups shifted their approach from initial corrective strategies to strategies to reduce conflict and distress, consistent with the view that EE reduces as problems resolve (Patterson, et al., 2005). As goals and strategies were adjusted, positive interactions focused on minimising stress and distress were used by carers who were accepting of the content of beliefs, consistent with findings that suggests low EE is associated with acceptance (Dorian, et al., 2008).

Contrary to the findings of Onwumere, et al., (2016), once carers adjusted to UBs they were able to make sense of beliefs. Fear of belief-related behaviours (Onwumere, et al., 2016) was not identified as a challenge in the analysed transcripts in this study. Narratives in this study did not support the view that negative attributions are higher in the context of psychosis, than in the context of dementia (Patterson, et al., 2005; Samuelsson, et al., 2001). The findings of this study suggest negative attributions are more significantly associated with a poor relationship history.

The current study uniquely positions the carers' motivation as critical to the process of adjustment, and considers the results in the context of attachment literature, which provides a framework for understanding variability in carer motivation.

Extant research supports the hypothetical links between carers' early attachment and their functioning as a carer. Insecure attachment elements within secure attachment patterns may be activated during times of threat (Crittendon, 2006), accounting for fluctuating EE. Transmission of values such as empathy and compassion, represented in this study as caring and relationship values, occur through early attachment relationships (Bretherton, et al., 1997), and secure attachments confer resilience in carers (Fonagy, Steele, Steele, Higgitt, &

Target, 1994). Attachment models may also explain the challenges some carers face during interactions with services and other support (Bartholemew & Horowitz, 1991).

The acceptance and commitment therapy model hypothesises a connection between holding values consistent with current roles and relationships, acceptance, and wellbeing (Harris, 2009). This corresponds with the findings of this study. Carers who had dominant values consistent with caring were accepting of the carer role and UBs, and experienced positive outcomes, whereas carers whose values appeared to conflict with caring, experienced more difficult emotions, higher stress and were not accepting of the carer role or UBs.

Study Strengths

This study met the standards for effective grounded theory research set out by Corbin & Strauss (1980). It used a clear epistemological framework for comparing and contrasting first person accounts of caring in the context of UBs. It explored UBs in the context of different diagnoses, incorporating the views of a range of family carers to explore similarities and differences. A model was developed that accounts for carer outcomes, providing a framework from which the hypotheses can be further tested and which can assist clinicians in effectively targeting resources to carers.

The study followed the analytical processes described by Corbin and Strauss (2008), demonstrating theoretical sampling, theoretical sensitivity, and reaching theoretical saturation. Analysis involved constant comparison, and used open, axial and selective coding. An iterative process led to the parallel development of the coding structure and model. In addition to following recognised processes for GT data collection and analysis, this study meets the criteria of the quality assessment framework as set out in Walsh and Downe (2006).

Limitations

The study may have benefitted from recruitment of additional participants in verifying the model however due to time and recruitment constraints further verification was precluded. However, it is not felt that this has influenced the nature of the main findings. The recruitment strategy relied on referrals from clinicians, potentially confining the recruitment to those participants that clinicians felt would be amenable to approach. Participants often self-select in their agreement to participate, feeling that they have something particularly positive or negative to contribute. It is therefore possible that some experiences may not have been elucidated. Examination of demographic data indicates there may be carer experiences that are not accounted for adequately. The type of UBs most commonly presented in the context of psychosis were paranoid beliefs so findings may not represent carer experiences of other types of beliefs, such as grandiose beliefs. Furthermore, until the final confirmatory stage there was no analysis of accounts of parent carers of sons. This may explain the absence of fear of behavioural consequences of UBs indicated in the research of Onwumere, et al., (2016). The maternal carer in the final phase of this study did indicate that she had in the past experienced fear in the context of UBs and this impacted on her ability to accept them. This is a potential area for further research. All carers were white British carers resident in North West England and all presented western, broadly medicalised understandings of psychosis and dementia. Cultural homogeneity and sample size may limit generalisability of the findings.

Future Research

Future research could usefully focus on: Testing the ‘4 types’ of carer experience and adjustment identified in the model, in wider samples; testing the link between motivation and outcome in more culturally diverse populations; and further testing of the relevance of

attachment theory, and its hypothesised connection to acceptance and outcomes. Future research should also seek to incorporate a wider range of types of UBs. Suggested interventions for carers could also be subject to evaluation for acceptability, and impact on long term outcomes.

Clinical Implications

Many carers felt that they lacked the knowledge they needed to intervene and support a person experiencing UBs, particularly during the early stages of caring, and suggested support and information was not easy to source. Carers also experienced barriers in communication with services that they felt hindered caring efforts. This highlights the importance of the need for family intervention and support recommended by the National Institute for Health and Care Excellence (NICE) (NICE, 2006; 2014) and the potential utility in the 'Triangle of Care' model (Hannan, 2013) which facilitates greater openness between services, the carer and the cared-for-person.

The current study suggests that there are qualitatively different 'types' of carers, who have different needs. All carers who are motivated by primary motivating factors, illustrated on the blue and green pathways would benefit from early intervention to expedite attainment of psychosocial understanding to enhance their natural formulation and problem-solving skills and optimise self-care. Those facing the greatest burden and contextual stressors, illustrated on the green dotted pathway, would be the greatest beneficiaries of intervention, suggesting justification of the potential costs of providing temporary supplementary care to facilitate participation. Incorporating acceptance and commitment therapy approaches within interventions for carers would be likely to enhance emotional coping and cognitive flexibility. The narratives of those achieving a 'positive' outcome suggest that these may be the mechanisms that facilitate 'positive' outcomes.

Carers who care in the absence of primary motivating factors, illustrated on the orange pathway, are less likely to benefit from carer interventions. Difficult emotions appear to prevent access to knowledge that may facilitate positive caring even when this knowledge is 'known'. Such carers are likely to experience a greater benefit from regular supplementary and respite care to alleviate burden, indirectly increasing coping resources.

Conclusions

Caring in the context of UBs presents significant additional challenges. However, this study suggests carers can adjust, accept and respond in helpful ways to UBs, resulting in a lower perception of burden. This study suggests that outcomes for carers are dependent on the value of the relationship to the carer, their values, and having sufficient support to ameliorate the impact of contextual stressors. Learning takes place through access to information, services and via experience over time. A lack of readily available information makes this an effortful process. High levels of stress and the absence of primary motivators preclude accessing or utilising the knowledge that can facilitate understanding and acceptance. A challenging relationship history precludes motivation to adapt, with significant further negative consequences for carers and those they care for. Despite the high frequency of overall 'good' or 'positive' outcomes, almost all carers felt that they needed further knowledge and understanding. This suggests a need for early interventions for carers comprising easily available comprehensive information and support to enhance coping and outcomes and expedite the adjustment process.

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Appendices

Appendix A

Author Guidelines for systematic review

Psychology and Psychotherapy: Theory, Research and Practice

Impact Factor: 1.627

Author Guidelines

Psychology and Psychotherapy: Theory Research and Practice (formerly The British Journal of Medical Psychology) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders. Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies. The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of psychopathology or innovative forms of therapy and meet scientific criteria through appropriate use of single case experimental designs.

All papers published in Psychology and Psychotherapy: Theory, Research and Practice are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Length

All articles submitted to PAPT must adhere to the stated word limit for the particular article type. The journal operates a policy of returning any papers that are over this word limit to the authors. The word limit does not include the abstract, reference list, figures and tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length (e.g., a new theory or a new method). The authors should contact the Editors first in such a case.

Word limits for specific article types are as follows:

• Review papers: 6000 words

Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

•Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template. When entering the author names into Editorial Manager, the corresponding author will be asked to

provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.

• The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.

• All Articles must include Practitioner Points – these are 2-4 bullet points, in addition to the abstract, with the heading 'Practitioner Points'. These should briefly and clearly outline the relevance of your research to professional practice.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.

• Manuscripts describing clinical trials must be submitted in accordance with the CONSORT statement on reporting randomised controlled trials (http://www.consort-statement.org).

• Manuscripts describing systematic reviews and meta-analyses must be submitted in accordance with the PRISMA statement on reporting systematic reviews and meta-analyses (http://www.prisma-statement.org).

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

Full Guidelines can downloaded from: http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8341/homepage/ForAuthors.html

Appendix B

Author guidelines for empirical research paper

British Journal of Psychology

Impact Factor: 3.139

Author Guidelines

The Editorial Board of the British Journal of Psychology is prepared to consider for publication:

(a) reports of empirical studies likely to further our understanding of psychology

(b) critical reviews of the literature

(c) theoretical contributions Papers will be evaluated by the Editorial Board and referees in terms of scientific merit, readability, and interest to a general readership.

All papers published in The British Journal of Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Length

Papers should normally be no more than 8000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.

• The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention, results or conclusions of the article.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

If you need more information about submitting your manuscript for publication, please email Melanie Seddon, Managing Editor (bjop@wiley.com) or phone +44 (0) 1243 770 108.

Full guidelines can be downloaded from:
http://onlinelibrary.wiley.com/journal/10.1111/%28ISSN%292044-8295/homepage/ForAuthors.html

Appendix C

Quality Assessment Criteria (Walsh & Downe, 2006)

Table 4 Summary criteria for appraising qualitative research studies.

Stages	Essential criteria	Specific prompts
Scope and purpose	Clear statement of, and rationale for, research question/aims/purposes	• Clarity of focus demonstrated • Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing • Link between research and existing knowledge demonstrated
	Study thoroughly contextualised by existing literature	• Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both
Design	Method/design apparent, and consistent with research intent	• Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting appropriate
	Data collection strategy apparent and appropriate	• Were data collection methods appropriate for type of data required and for specific qualitative method? • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? • Was triangulation of data sources used if appropriate?
Sampling strategy	Sample and sampling method appropriate	• Selection criteria detailed, and description of how sampling was undertaken • Justification for sampling strategy given • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained
Analysis	Analytic approach appropriate	• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) • Was it appropriate for the qualitative method chosen? • Was data managed by software package or by hand and why? • Discussion of how coding systems/conceptual frameworks evolved • How was context of data retained during analysis • Evidence that the subjective meanings of participants were portrayed • Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance • Did research participants have any involvement in analysis (e.g. member checking) • Evidence provided that data reached saturation or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion/rationale if it was not
Interpretation	Context described and taken account of in interpretation	• Description of social/physical and interpersonal contexts of data collection • Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena
	Clear audit trail given	• Sufficient discussion of research processes such that others can follow 'decision trail'

Table 4 (*continued*)

Stages	Essential criteria	Specific prompts
	Data used to support interpretation	• Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation led to conclusions
Reflexivity	Researcher reflexivity demonstrated	• Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher's influence on stages of research process • Evidence of self-awareness/insight • Documentation of effects of the research on researcher • Evidence of how problems/complications met were dealt with
Ethical dimensions	Demonstration of sensitivity to ethical concerns	• Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • Evidence of fair dealing with all research participants • Recording of dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed
Relevance and transferability	Relevance and transferability evident	• Sufficient evidence for typicality specificity to be assessed • Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies • Discussion of how explanatory propositions/emergent theory may fit other contexts • Limitations/weaknesses of study clearly outlined • Clearly resonates with other knowledge and experience • Results/conclusions obviously supported by evidence • Interpretation plausible and 'makes sense' • Provides new insights and increases understanding • Significance for current policy and practice outlined • Assessment of value/empowerment for participants • Outlines further directions for investigation • Comment on whether aims/purposes of research were achieved

Appendix D

Table of quality assessment scores

Author	Scope & Purpose		Design		Sampling Strategy	Analysis	Interpretation			Reflexivity	Ethical	Relevance and transferability
	Clear Research Question	Literature Review	Method design appropriate to research	Data collection			Context described	Clear Audit trail	Data Used to Support interpretation			
Boyd & Gumley, (2007)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y (9)
Campbell, et al., (2007)	Y	Y	N	Y	Y	Y	Y	N	Y	N	Y	Y (9)
Drinnan & Lavendar, (2004)	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y (11)
Engqvuist & Nilsson, (2013)	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y (10)
Jones, et al., (2016)	Y	Y	N	Y	Y	Y	Y	N	Y	N	Y	Y (9)
Larsen, (2004)	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y (10)
Rhodes & Jakes, (2004)	Y	Y	N	Y	Y	N	Y	Y	Y	N	Y	Y (9)
Rhodes & Jakes, (2010)	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y (11)
Rieben, et al., (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y (11)
Stopa, et al., (2012)	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y (11)
Roe, Chopra, & Rudnick, (2004)	*Y*	*Y*	*Y*	*Y*	*Y*	*Y*	*Y*	*N*	*N*	*N*	*N*	*Y (8)*
Stanghelli & Ballerini (2010)	*Y*	*Y*	*N*	*N*	*N*	*N*	*Y*	*N*	*N*	*N*	*N*	*Y (4)*

NB. Papers scoring below 9 (shown in italic text) were excluded from the review.

Appendix E

Systematic Review Coding Structure & Analysis

Cognitive Processing	**Predisposing Factors**
Making sense of experiences - using metaphor	Making sense of cause - childhood experiences
Predisposing beliefs and thinking style	Making sense of cause - stress, trauma
Literal interpretation of metaphorical thinking	Making sense of cause - substance use
Unusual reasoning = unusual belief	Pathways to delusions
The Self in Social and Cultural Context	Sudden onset
Bad self	**Recovering**
Split self	**Coping**
Unusual beliefs link to local cultural norms	Coping - medication
Vulnerable self	Coping Strategies - cognitive
Discriminating Unusual Beliefs	Coping Strategies - fluid
Beliefs as an out of control entity	Coping Strategies - influenced by context
Discriminating UBs from other beliefs	Coping Strategy - integration
Overwhelming experience	Coping strategy - sealing over
Recognition of unusualness	**Making Sense of Experience**
Experience of Unusual Beliefs	Active dynamic processing of competing explanations
Positive v negative experience	Ambivalence in explanations
Unusual beliefs as a gift	Creating new meaning
Unusual beliefs as dangerous or risky	Integrating belief systems
Unusual beliefs as empowerment	Letting go of beliefs is painful
beliefs as figuratively transformative	Making sense - using a single belief system
Unusual Beliefs as frightening	Moving towards a culturally shared understanding
Unusual Beliefs as Unpleasant	Valued experience
Purpose	**The Role of Others**
Complexity in experience - threat and defence	Others makng sense of beliefs
Unusual beliefs - have a purpose	Over validation of unusual ideas
Reacting to UBs	Professional practice and unusual beliefs
Response - anxiety	Search for validation
Response - Dissociation	**Predisposing Factors**
Response - Escape avoidance	Making sense of cause - childhood experiences
Triggering Onset	Making sense of cause - stress, trauma
Reasoning in isolation	Making sense of cause - substance use
Integration of experiences	Pathways to delusions
Unusual beliefs - making sense of discomfort	Sudden onset

Phase 3: Identified Themes

Theme 1: Reflecting on the cause Negative life experiences Substance misuse Vulnerable & bad self The influence of cultural context	**Theme 3: The experience of beliefs** Purpose of beliefs Positive v negative experiences Overwhelming and out of control Recognising unusual qualities
Theme 2: Evolution of beliefs Making sense of discomfort Thinking and reasoning Integrating experiences Reasoning in isolation	**Theme 4: Recovering** Searching for validation Coping Making sense of experiences

Appendix F

Researcher Reflective Memo

Reflexive Statement

Having had personal experience of supporting and caring for family members who have experienced UBs I noticed differences in my own responses and was curious why it seemed natural in the context of dementia to go along with beliefs, while in the context of psychosis the responses came less naturally and there was more uncertainty about how to respond.

On entering a career in psychology, I worked in settings where similar challenges presented, and the underlying philosophies of care seemed very different in the context of different 'illnesses'. There remains a poor understanding of what the most helpful approaches are in the context of UBs, for clinicians themselves, and approaches to share with families. It is hoped that this research and systematic review together will start to build a picture of the most helpful ways for families to cope with UBs, and engage positively with the person experiencing them.

Expectations of findings

I expect that people will be naturally more accepting and accommodating of UBs in the context of organic difficulties. I also think that as there is a shared consensus of how to approach UBs in the context of dementia, families will have more access to consistent information and more support from services, which will facilitate positive coping.

I anticipate that there will be several stages to adjusting to UBs, and due to the available resources and understanding in dementia, carers may be facilitated to adjust to UBs more effectively, where an absence of information may prevent effective adjustment in psychosis. Other barriers that I feel may influence adjustment to UBs is related to previous research in carers, and includes factors such as role conflict, financial and social resources, and perception of burden.

I am curious as to whether time since diagnosis will influence outcomes in psychosis, as the context of services has changed markedly during the last 20 years. It will be of interest to note whether new understanding of psychosis has influenced the way families think about the person they are supporting.

Appendix G

IRAS Ethical Approval Letter

NHS
Health Research Authority
Yorkshire & The Humber - Leeds East Research Ethics Committee
Room 001
Jarrow Business Centre
Rolling Mill Road
Jarrow
Tyne and Wear
NE32 3DT

Telephone: 0207 1048 088

17 March 2016

Professor Rhiannon Corcoran
University of Liverpool
Department of Psychological Sciences
Institute of Health, Psychology and Society
Rm B211 Waterhouse Building
L69 3GL

Dear Professor Corcoran

Study title:	**Carers' Experiences of Unusual Beliefs: An exploration of burden and acceptance in psychosis and dementia**
REC reference:	**16/YH/0121**
Protocol number:	**UoL0001193**
IRAS project ID:	**201120**

The Proportionate Review Sub-committee of the Yorkshire & The Humber - Leeds East Research Ethics Committee reviewed the above application on 14 March 2016.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Katy Cassidy, nrescommittee.yorkandhumber-leedseast@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a **favourable** ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

Summary of discussion at the meeting

Ethical issues raised, noted and resolved in discussion:

The Sub-Committee raised all queries in email correspondence with the applicant.

Social or scientific value; scientific design and conduct of the study

The PR Sub-Committee requested further clarification about the focus group and whether this would be part of the research. If so, it was requested for information about the recruitment arrangements, the likely location and appropriate documentation (e.g. consent forms, focus group schedule of broad questions/themes) were provided.

Clarification was provided that the focus group was considered to be part of the research. Updated information was provided about the use of and recruitment of the focus group. A recruitment poster, information sheet, consent form and schedule were also submitted for review.

The PR Sub-Committee queried that if participants were being interviewed in the shared home with the person for whom they care whether the patient would be in the room or specifically excluded. It was noted that this should be highlighted in the participant information sheet in order for the carer to have a change to decide where the interview would be conducted.

The participant information sheet was updated to include a statement explaining that the researchers would like to interview participants without family members present and alternative arrangements could be made if a private space to conduct the interview was not possible in their own homes.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

The PR Sub-Committee queried whether it would be possible that carers might talk about the service users and potentially breach their confidentiality. Given that the service users were not being asked about the study, it was queried whether this might be a risk.

It was explained that it was possible that the experience of participants could be spoken about by the carers, however the research would have no information to link any service user or other information which could lead to the identification of an individual. It was also explained that information regarding third parties would not be required, other than what initially brought the carers attention to the fact that the symptom was being experienced. Participants would be redirected to discuss their own experiences if any personal information of third parties was disclosed, none of this information would be considered or included as part of the research.

Informed consent process and the adequacy and completeness of participant information

The PR Sub-Committee noted that point 5 of the consent form should be written in simpler language, in order to ensure that participants clearly understand the use of quotations.

The consent form was amended to clarify the use of verbatim quotes and resubmitted.

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Study Poster]	1	25 February 2016
Copies of advertisement materials for research participants [Focus Group Recruitment Poster]	1	09 March 2016
Covering letter on headed paper [Application Covering Letter]	v1	25 February 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Cover]	1	25 February 2016
GP/consultant information sheets or letters [Letter to Clinician]	1	25 February 2016
GP/consultant information sheets or letters [Clinician Flyer]	1	25 February 2016
Interview schedules or topic guides for participants [Sample interview schedule]	1	27 November 2015
Interview schedules or topic guides for participants [Focus Group Schedule]	1	09 March 2016
Letter from sponsor [Sponsorship approval letter]	1	18 January 2016
Letters of invitation to participant [Participant Invitation]	1	25 February 2016
Non-validated questionnaire [Demographic Questionnaire]	1	27 November 2015
Other [Letter addressing committee queries]	1	10 March 2016
Participant consent form [Opt In Form]	1	25 February 2016
Participant consent form [Study Consent Form]	2	09 March 2016
Participant consent form [Focus Group Consent Form]	1	09 March 2016
Participant information sheet (PIS) [Focus Group Participant Information Sheet]	1	09 March 2016
Participant information sheet (PIS) [Study Participant Information Sheet]	2	09 March 2016
REC Application Form [REC_Form_04032016]		04 March 2016
Referee's report or other scientific critique report [Research Review Committee Approval]	1	30 October 2015
Research protocol or project proposal [Research Proposal v3]	3	28 October 2015
Summary CV for Chief Investigator (CI) [CI Research CV]	1	27 November 2015
Summary CV for student [Student CV]	1	25 February 2016
Summary CV for supervisor (student research) [Methodological Supervisor CV]	1	27 January 2016
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Protocol Flowchart]	1	25 February 2016

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

16/YH/0121	**Please quote this number on all correspondence**

Yours sincerely
pp

Sarah Brothers

Dr Rhona Bratt
Chair

Email: nrescommittee.yorkandhumber-leedseast@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

"After ethical review – guidance for researchers"

Copy to: *Mr Alex Astor, University of Liverpool*

Ms Karen Bruce, Mersey Care NHS Trust

Yorkshire & The Humber - Leeds East Research Ethics Committee

Attendance at PRS Sub-Committee of the REC meeting held by correspondence

Committee Members:

Name	*Profession*	*Present*
Dr Rhona Bratt (Chair)	Retired Multimedia Project Manager	Yes
Miss Jennifer Blaikie	Senior Research Ethics Administrator	Yes
Dr Deborah Jane Fox	Senior Lecturer in Nursing	Yes

Also in attendance:

Name	*Position (or reason for attending)*
Miss Sarah Prothero	REC Assistant

Appendix H

Research letter to participants

Mersey Care NHS
NHS Trust

[Address] [Clinician name/address]

[Date]

Dear [Name]

Research Study: Carers' Experiences of Unusual Beliefs

We would like to introduce you to a research project that we think you may be interested in taking part in. The study is being carried out by researchers at the University of Liverpool who are interested in the experience of people who have helped to support a family member or friend who has experienced unusual beliefs, commonly known as 'delusions'.

The study aims to find out more about the impact of unusual beliefs on the wellbeing and experience of people who have supported, or are supporting people who have these experiences. This has not been researched before, so you have some very important things you can teach us about the best way to support people experiencing unusual beliefs, but also about how we can support friends and family members, who we meet in our services, to cope with these experiences.

The lead researcher is Julia Taylor, a Trainee Clinical Psychologist, and the Chief Investigator is Professor Rhiannon Corcoran, who is supervising this study. The researchers would like to find out about the challenges you faced, but also what helped you to cope and whether there were things that you feel you managed well.

If you think you would like to participate in this study, please complete the attached consent and opt in forms, and demographic questionnaire and return them in the pre-paid envelope to the researchers. The researchers will then contact you to discuss further participation in the study and possibly visiting you to carry out an interview that may take up to an hour.

If you think you would like to take part in this study please read the more detailed study information enclosed. If you have any questions about the research you may contact **Julia Taylor** on **07519 896552** and she will be happy to talk to you about the study and answer any questions you have.

Please note you are under no obligation to participate in this research, and if you decide not to, it will not have any impact on the care you and your friend or relative receive. If you change your mind about taking part you can contact the researchers at any time and they will not make any further contact with you.

Yours sincerely

[Clinician Name]

Enclosures:

- Participant Information Sheet (please read this carefully before deciding whether to take part, and keep this for future reference)
- Consent Form (please complete and return in the pre-paid envelope)
- Demographic Questionnaire (please complete and return in the pre-paid envelope)
- Opt in form for you to provide your contact details to the researchers (please complete and return with the consent form and demographic questionnaire).

Appendix I

Participant Information Sheet

Participant information sheet

Title of Project: Carers' Experiences of Unusual Beliefs: An exploration of burden and acceptance in psychosis and dementia

You are being invited to take part in a research study because you have been identified by a clinician in Mersey Care NHS Trust as someone who looks after a family member who sometimes expresses unusual beliefs (commonly referred to as 'delusions'), or you have contacted the researchers after seeing our study being advertised by Mersey Care NHS Trust.

The study consists of completing a brief questionnaire and a semi-structured interview about your experiences of caring for someone who experiences unusual beliefs. Overall the researcher may spend up to one and a half hours with you.

Before you decide to take part it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of this study?
It has been suggested that unusual beliefs are one of the most difficult experiences carers face when looking after loved ones, yet little is understood about how carers cope with this. Through this research we hope to improve the understanding of what it is like to care for a person who experiences unusual beliefs and to find out what helps carers cope with and accept this situation. The aim of this study is to understand the impact of unusual beliefs on the carer and how carers cope.

Why is this research useful?
Carers' experiences of looking after friends and family members who have become unwell have been widely researched, but the experience of coping with unusual beliefs is not well understood and has not previously been explored, despite many carers finding this one of the most difficult and upsetting symptoms that they have to cope with.

Directly reported experiences of coping with unusual beliefs will be extremely useful to help identify the best ways to support carers and reduce the stress and burden of caring. It can inform how carer support may be improved.

What are the possible disadvantages and risks of taking part?
Caring for people who experience unusual beliefs can be distressing and may lead to difficulties in family relationships, fatigue and stress. Talking about these experiences with the researcher may be upsetting. If you feel that the interview is difficult for you at any point then you can take a break or postpone the session until another time. If you do not feel up to taking part at any time then please just let the researcher know and participation can be postponed or cancelled.

Should you wish to stop the study you can do so immediately. Should you wish to skip a question during the interview this is also fine. If you feel you need to talk to someone further

about any issues that have been raised then it is recommended that you contact your GP for further support.

What are the benefits of taking part?
There are no benefits to you directly, however sometimes carers, whether professional or informal, report negative experiences of caring. This study aims to understand this experience and contribute to the improvement of support for carers in the future.

Do I have to take part?

It is up to you to decide whether you would like to be involved in this study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to decline or withdraw at any time and **this will not affect any current or future care you, or the person you care for receives**.

What will happen if I consent to take part?
You will be asked to complete a brief questionnaire and participate in an interview about your caring experiences, specifically your experience of dealing with unusual beliefs. Your interview will be digitally recorded to be transcribed verbatim, and the interviewer may also make some brief written notes during the interview. This may take up to one and a half hours of your time. The researcher will visit you at home, however the researchers would like to interview you without other family members present. If you feel that a private space without interruption cannot be provided for the duration of the interview at home the researchers will endeavour to arrange an alternative location of your choice. Travel expenses will not be paid to participate in this study.
You will receive a voucher valued at £10 as a 'thank you' for taking the time to contribute to this research.

What will happen if I don't want to carry on?
You are free to withdraw at any time from the study without giving a reason and without it affecting your or your family member's future care. If you begin to complete the interview and decide you no longer wish to continue then you can stop at any time. If you chose to withdraw from the study any data you have provided will be destroyed.

Complaints
If you have a concern about any aspect of this study, you should contact the researchers using the details provided below and they will do their best to answer your questions. If you remain unhappy or have a complaint which you feel you cannot come to us with, then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Will my taking part be kept confidential?
All information you provide will be treated and stored confidentially, however if you told us anything that raised concerns about your safety or the safety of a vulnerable person, or regarding criminal activity, then we would have to break confidentiality and pass this information on to the appropriate authority. In this situation you would be made aware of what information would be reported and to whom.

The consent form containing personal information will be locked in a secure place, and only the research team will have access to it. Any data and written results will be anonymised in accordance with the Data Protection Act 1998.

What will happen to the results of the study?
The results of the study will be used to inform future research and contribute to the development of a model to understand the experience of carers when faced with unusual beliefs. Data collected from this study may be used to inform the types of services that would best support people's needs.

The data will be collected and anonymised so that the source of your information cannot be identified. This type of study often uses verbatim quotes that you may recognise, however other people will not be able to link quotes to any individual who has taken part in the study. The data will be analysed and written up for peer reviewed journals and for presentation at conferences.

Who is organising and funding this research?
This research is organised and funded by University of Liverpool as part of the Doctorate in Clinical Psychology.

Who has reviewed this study?
This study has been reviewed by DClinPsychol Research Committee, and before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the NHS Research Ethics Committee.

Finding out more
If you would like to discuss this study further or if there are any questions you would like to ask, please contact the Chief Investigator, Professor Rhiannon Corcoran at:

Institute of Psychology, Health and Society
Room B211, Block B 2nd Floor, Waterhouse Building
University of Liverpool
Liverpool, L69 3GL
0151 795 5365
rhiannon.corcoran@liverpool.ac.uk

If you wish to make a complaint or report any adverse effects resulting from participating in this research please contact the Chief Investigator in the first instance.

Thank you for taking the time to read this information sheet.

Appendix J

Consent Form

UNIVERSITY OF LIVERPOOL

Mersey Care NHS
NHS Trust

CONSENT FORM

Title of Project: Carers' Experiences of Unusual Beliefs: An exploration of burden and acceptance in psychosis and dementia

Name of Researcher: Julia Taylor

	Please initial box
1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that relevant anonymised data collected during the study, may be looked at by individuals from regulatory authorities, the NHS Trust or the University of Liverpool where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	☐
4. I agree that if I disclose information regarding my safety and the safety of vulnerable others then this information will have to be disclosed to the relevant authorities.	☐
5. I consent to the use of audio recording of interviews. I understand things I say may be quoted directly word for word in the published and shared research articles. I understand that these quotes will not be linked to my name or other identifiable information, and I give my consent to be directly quoted.	☐
6. I agree to take part in the above study.	☐

Name of Participant	Signature	Date
_____	_____	_____
Researcher	Signature	Date
_____	_____	_____

Appendix K

Demographic Questionnaire

UNIVERSITY OF LIVERPOOL

Mersey Care NHS
NHS Trust

Demographic Questionnaire

Carers' Experiences of Unusual Beliefs: An exploration of burden and acceptance in psychosis and dementia

Participant Number: ☐ (to be completed by researcher)

Diagnosis of your relative: Dementia Psychosis
(eg.. 'schizophrenia, bipolar, depression with psychosis')

Relationship to person cared for:

Mother	Spouse/Partner	Son	Friend
Father	Brother/Sister	Daughter	Other

Your Age: ☐ Age of person cared for: ☐

Are you cohabiting with the person you care for? Yes/No

Existing research suggests a number of factors affect the experience of caring. Answering the following questions will help us better understand the experiences you describe in your interview.

Time since onset of unusual belief:

less than 6 months	6 months -1 year	1 - 2 years
2 - 5 years	more than 5 years	

Approximate number of hours contact per day at the time unusual beliefs were being experienced:

Less than 2 hours	2 - 5 hours	5 - 10 hours	Over 10 hours

Number of years you spent in full time education:

Number of years you spent in part-time education:

At the time of starting the caring role were you in full time or part time employment?

Full Time Part Time Neither

Did your employment status change as a result of your role as a carer?

Yes No

At the time of caring were you also caring for others in your family, for example children/partner/parent?

Yes No

Were any of the people you were caring for experiencing a chronic or acute health difficulty or disability?

Yes No

How well do you think you cope with caring?

I find it hard to cope	I cope well some of the time	I cope well most of the time	I cope well all of the time

How well do you think you cope with unusual beliefs?

I find it hard to cope	I cope well some of the time	I cope well most of the time	I cope well all of the time

Appendix L

Demographic Data

P	Pseudonym	Diagnosis	Relationship to person cared for	Age of carer	Caring for	Age of person cared for	Cohabiting	Time since onset of UB	Hours of contact during UB experience	Years in education
1	Susan	Psychosis	Mother	56-65	Daughter	19-25	No	over 5 years	over 10 hours	-
2	David	Psychosis	Father	66-75	Daughter	36-45	Yes	over 5 years	2 - 5 hours	9-11
3	Nicola	Psychosis	Mother	56-65	Daughter	36-45	Yes	over 5 years	over 10 hours	9-11
4	Louise	Psychosis	Daughter	56-65	Father	Over 75	No	2 - 5 years	over 10 hours	13-16
5	James	Dementia	Spouse/partner	Over 75	Spouse/partner	Over 75	Yes	1 - 2 years	over 10 hours	13-16
6	Karen	Dementia	Daughter	46-55	Father	Over 75	No	1 - 2 years	2 - 5 hours	-
7	Emma	Psychosis	Mother	-	Daughter	36-45	No	over 5 years	over 10 hours	over 16 years
8	Rachel	Psychosis	Spouse/partner	36-45	Spouse/partner	36-45	Yes	2 - 5 years	over 10 hours	-
9	Chloe	Psychosis	Sibling	46-55	Sibling	46-55	Yes	over 5 years	over 10 hours	11-13
10	Marie	Dementia	Spouse/partner	66-75	Spouse/partner	66-75	Yes	2 - 5 years	over 10 hours	13-16
11	Mark	Dementia	Spouse/partner	66-75	Spouse/partner	66-75	Yes	1 - 2 years	over 10 hours	11-13
12	Laura	Dementia	Daughter	36-45	Mother	66-75	No	6 to 12 months	over 10 hours	13-16
13	Claire	Dementia	Daughter	46-55	Mother	Over 75	No	2 - 5 years	over 10 hours	over 16 years
14	Elizabeth	Psychosis	Mother	66-75	Son	46-55	No	over 5 years	under 2 hours	9-11
15	Alistair	Psychosis	Father	66-75	Son	46-55	No	over 5 years	2 - 5 hours	13-16

Demographic Data continued

P	Pseudonym	Employment status at onset	Employment status change	Other caring responsibilities	Additional needs	Coping with Unusual Beliefs	Coping with caring
1	Susan	Full Time	No	No	N/A	I cope well some of the time	I cope well some of the time
2	David	Part Time	No	No	N/A	I cope well some of the time	I cope well most of the time
3	Nicola	Full Time	No	No	N/A	I find it hard to cope	I cope well some of the time
4	Louise	Full Time	Yes	Yes	No	I find it hard to cope	I cope well most of the time
5	James	Not in employment	No	No	N/A	I find it hard to cope	I cope well most of the time
6	Karen	Not in employment	No	No	Yes	I cope well some of the time	I cope well some of the time
7	Emma	Full Time	Yes	No	N/A	I cope well some of the time	I cope well some of the time
8	Rachel	Full Time	Yes	Yes	No	I cope well most of the time	I cope well most of the time
9	Chloe	Full Time	No	No	N/A	I cope well most of the time	I cope well most of the time
10	Marie	Not in employment	No	No	N/A	I find it hard to cope	I cope well all of the time
11	Mark	Not in employment	No	No	N/A	I find it hard to cope	I cope well some of the time
12	Laura	Part Time	Yes	Yes	No	I cope well all of the time	I cope well some of the time
13	Claire	Full Time	Yes	Yes	No	I cope well some of the time	I cope well some of the time
14	Elizabeth	Not in employment	No	No	N/A	I find it hard to cope	I find it hard to cope
15	Alistair	Not in employment	No	No	N/A	I find it hard to cope	I find it hard to cope

NB. Participant 5 was coping with a ‘failure in caregiving’ that is reflected in his evaluation of coping at the time of questionnaire completion. Narrative during the interview contradicted his self-evaluation.

Appendix M

Phase 1: Semi-structured Interview Schedule

Interview Schedule – Phase 1

1. Some carers say that unusual beliefs/delusions are the most stressful symptoms to cope with, would you agree?
   why do you think that is the case?
2. Can you tell me about the nature of the unusual beliefs?
3. What were the first things you did in response to the unusual beliefs being expressed? (Prompt: Did you try to help, or address the beliefs?)
4. How managing the experience of unusual beliefs affect you? (Prompt: How did you feel/think)
5. Have there been any other consequences of the unusual beliefs for yourself and your family?
6. What helped you to cope with unusual beliefs?
7. Do you, or would you deal unusual beliefs differently now? (Prompt: practically/strategies)
8. Have your thoughts or feelings about unusual beliefs changed? (Prompt: do you feel the same way you did the first time you heard any unusual beliefs)
9. (If different) Why do you think your experience of managing or coping with unusual beliefs have changed?
10. Is there any advice you would pass on to others who find themselves caring for a person experiencing unusual beliefs?
11. What do you think would have helped you to cope with unusual beliefs for example, are there any recommendations you would like to make to services supporting families?

Appendix N

Phase 2: Semi-structured Interview Schedule

Interview Schedule – Phase 2

Relational

How would you describe your relationship did you have with X before they received a diagnosis? Has this changed?

Do you feel the relationship between you and X has changed? How?

How did you resolve any arguments or difficulties in your relationship? Is this different now?

Individual

Did you expect to find yourself supporting and caring for X at some point in your life? Does it feel ok for you to take on this role? Why do you think you have taken on the role?

Did you have goals for the future before taking on this role? What kind of things were important to you? What do you feel about those goals now?

Beliefs

What is the most difficult aspect of UB's for you to cope with?

When the UBs were being expressed, was this challenging for you? If so how?

What did it mean for you, and for X, when you heard the unusual beliefs for the first time?

What did you feel? Why do you think you felt that way?

What is the most difficult thing to cope with when X is saying unusual things?

How do you make sense of the unusual beliefs? Do you have an explanation for why they happen? Can see any explanation for the content of the belief, why they might think those things?

What do you hope for regarding X's unusual beliefs, what is important for you to help them achieve?

Do you feel you can do anything about the beliefs? Can you make X's experience any different?

Do you feel that you have changed at all through the experience of supporting someone with UBs? How?

Do you feel like the way you live your life has changed? Are your priorities or perspectives different? How

Have any of these changes felt like positive changes?

What do you find is the most effective way of responding to UBs? Why do you think that is the best way?

Appendix O

Hierarchical Coding Structure

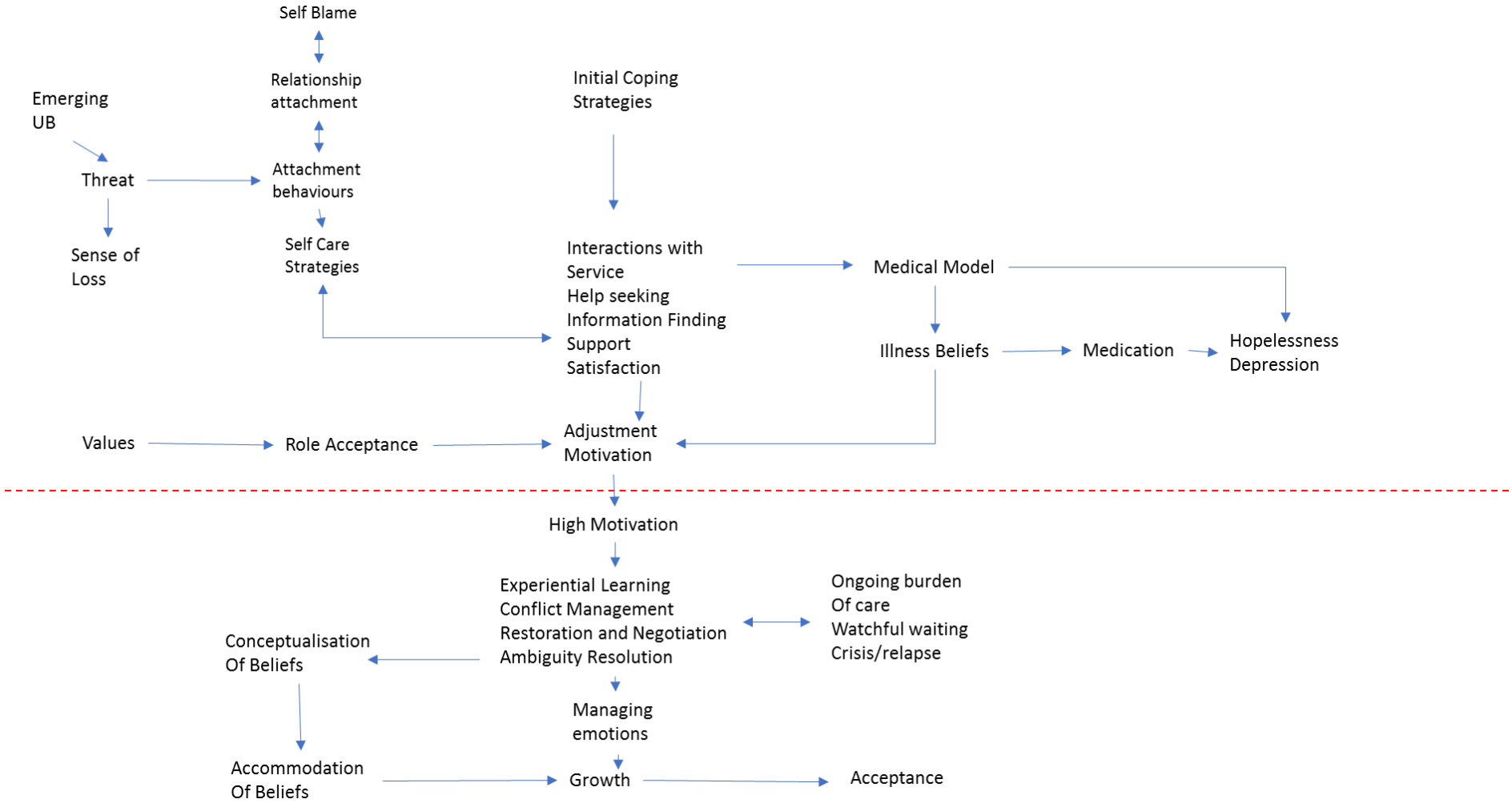
Accommodating Unusual Beliefs	**Adjustment**
Carer Goals	**Professional Consultation**
Dementia	Illness and Diagnosis
Psychosis	Illness Beliefs
Accommodating Unusual Beliefs	**Adjustment**
Ongoing Stressors	**External Processes**
Dementia	Advice Seeking
Exhaustion and sleep deprivation	Finding and accessing services
Future care and care transitions	Information Searching
Overwhelm	Learning (excl experiential)
Accommodating Unusual Beliefs	**Adjustment**
Ongoing Stressors	**Intraindividual Carer Processes**
Psychosis	Accepting 'illness'
Future care and safety	Accepting 'new' relationship
Risk and safety	Accepting Person
Watchful waiting, anticipating relapse	Externalising cause
Accommodating Unusual Beliefs	Making sense of beliefs
Strategies	Processing new information
Dementia	Protecting - absorbing conflict
Distraction	Protecting - hiding emotions
Facilitating goal directed behaviour	Reflecting
Living in their world	Taking responsibility
Manipulating Emotions	**Adjustment**
Playing along	**Relational Processes**
Predictable but flexible routine	Active Listening
Reassuring	Creating and supporting dialogue
Accommodating Unusual Beliefs	Experiential Learning
Strategies	Negotiating
Psychosis	Re-establishing Trust
Allowing belief while sharing own	Relationship role change
Empathising with perspective and emotion	Repairing relationship
Inviting dialogue	
Negotiating helpful strategies	
Non judgemental exploration	
Suggesting alternative perspective	
Supportive evidence search	

Carer	**Crisis**
Attachment Behaviours	**Onset**
Negative	**Meaning**
Positive	Change
Carer	Loss
Role	**Crisis**
Acceptability	**Onset**
Appropriateness	**Threat**
Carer	Identity
Coping Strategies	Reality or understanding
Family Support	Relationship
Negative	Values
Positive	**Crisis**
Meaningful Activity	**Outcome of Early Strategies**
Meaningful Roles	Impact on cared for person
Relationships with services	Impact on Carer
Negative	Impact on relationship
Positive	**Crisis**
Social Relationships	**Reactive Behaviours**
Negative	Arguing
Positive	Correcting
Carer	**Crisis**
Early Attachment	**Reactive Emotion**
Carer	Anger
Individual Carer Factors	Confusion
Personality	Distress
Prior experience or knowledge	Isolation and loneliness
Motivation	Panic and anxiety
Primary Motivators	Shock
Relationship Importance	
High	**Outcome**
Low	**Acceptance of beliefs**
Relationship Values	High acceptance
Carer	Low Acceptance
Motivation	**Outcome**
Secondary Motivators	**Evaluation of coping**
Emotion	Negative coping statements
Repaying a Debt of Care	Positive coping statements
Responsibility	**Outcome**
Carer	Intrapersonal Growth
Relationship	**Outcome**
Attachment	'New relationship' acceptance
Identity	**Outcome**
Other Values	**Stress and Burden**
Relationship Values	High
	Low

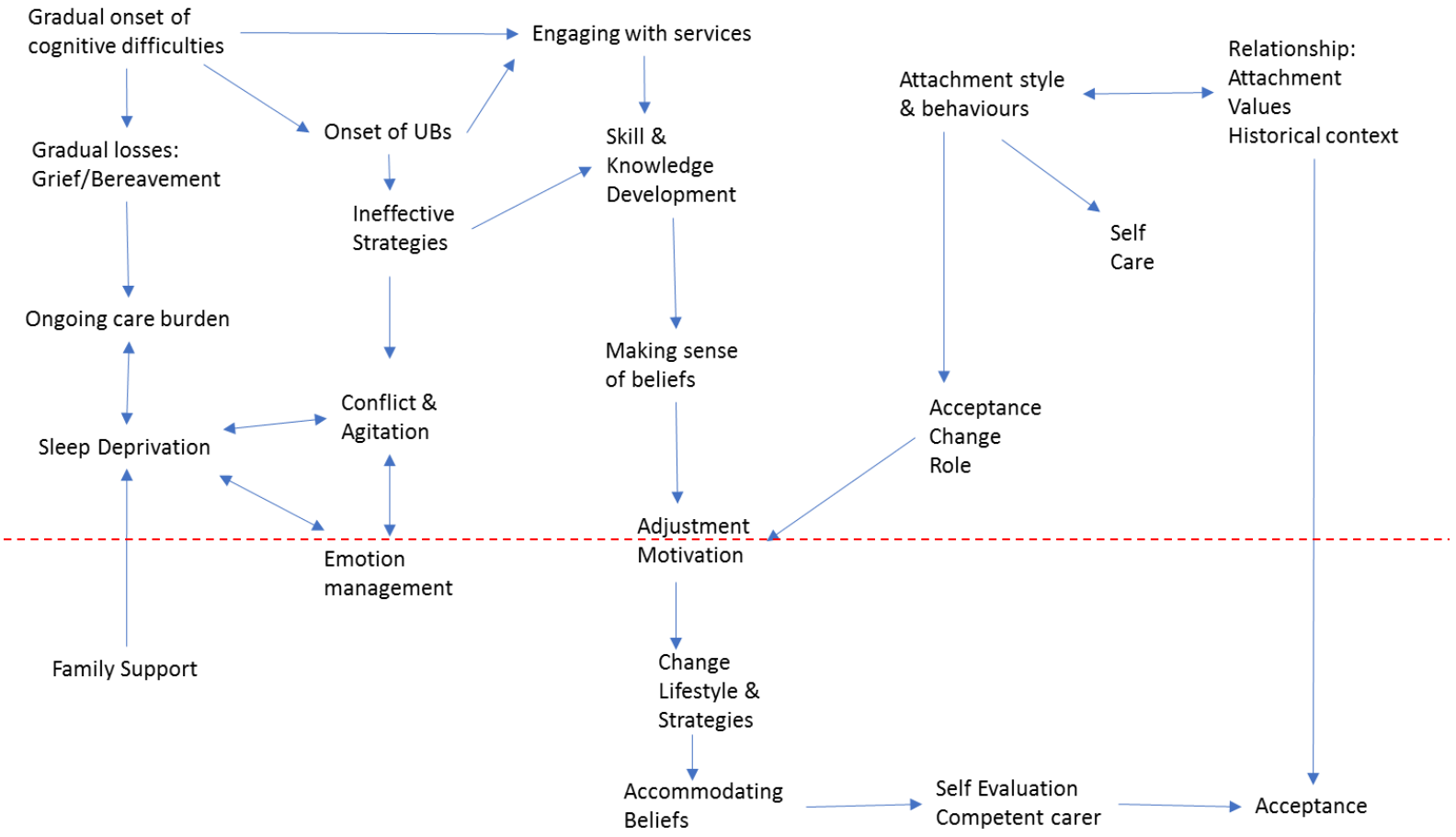
Appendix P

Preliminary Models

Phase One: Psychosis model of carers' experience

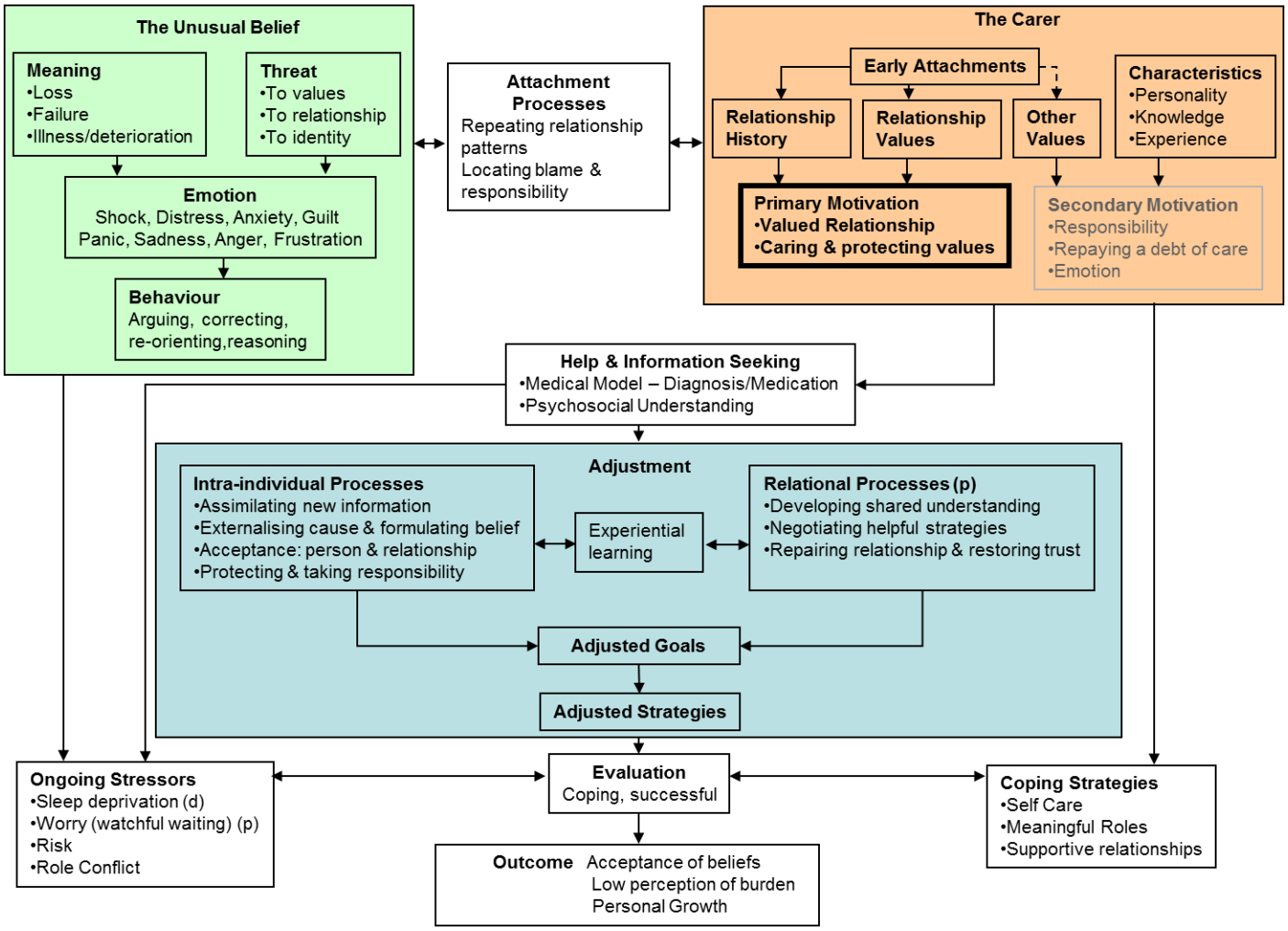


Phase One: Dementia model of carers' experience

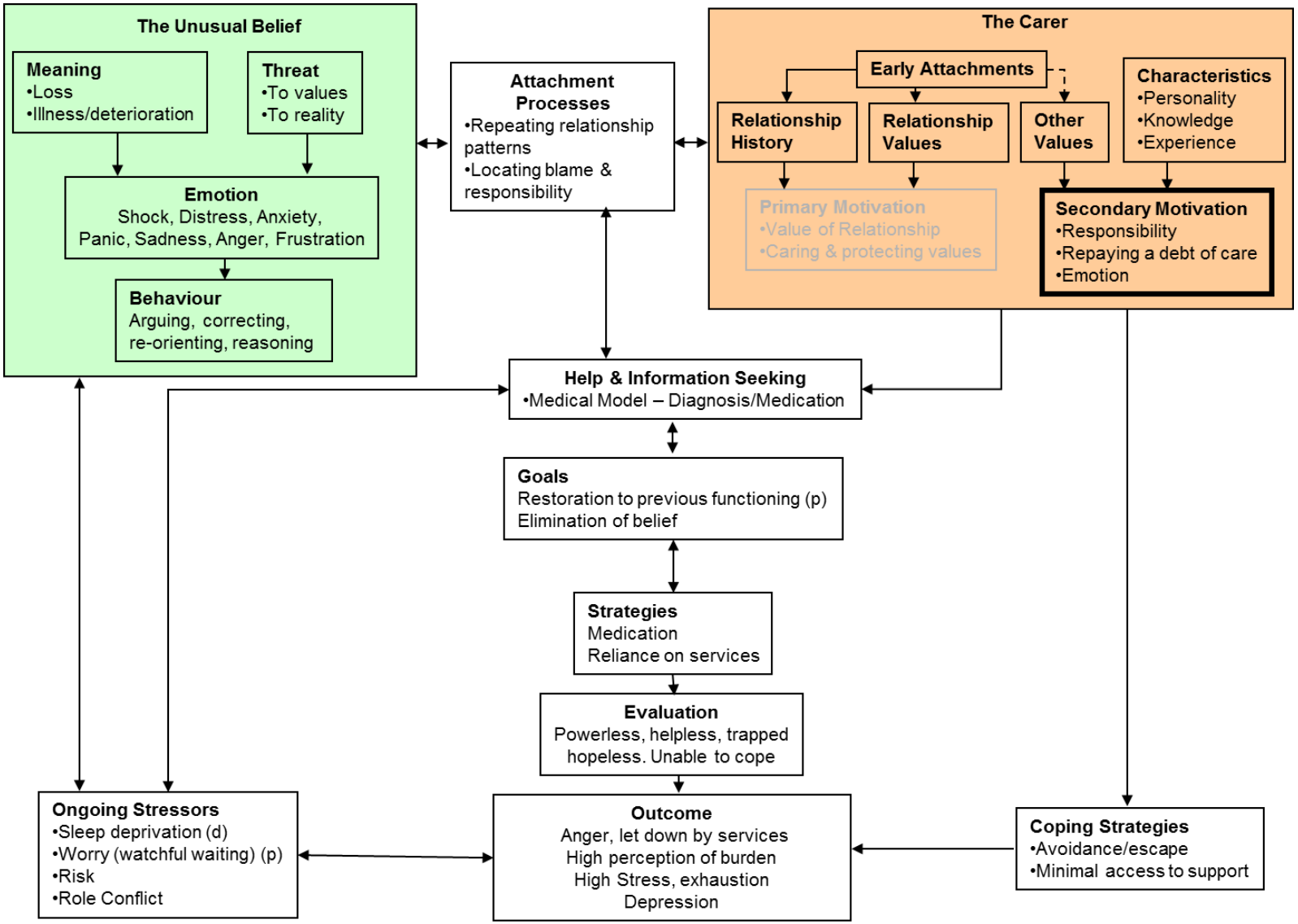


Appendix Q

Emerging Models: Carers Experience of Unusual Beliefs



Carers' experience of UBs illustrating no adjustment



Appendix R

Storyline memo

Carers of people experiencing unusual beliefs face several challenges. The content of beliefs is often challenging to the carers sense of reality, their values, their attachment relationship with the person or their sense of identity within the relationship. Challenges to highly valued aspects of their lives and values will elicit the strongest emotions. Carers initially feel compelled to correct unusual beliefs. The impact of beliefs will disrupt the process of the relationship and the process of caring, with carers expressing a sense of loss.

Motivation is critical to the process of caring. Many carers have strong family or relationship values that compel them to care for the person, and most have experienced a 'good enough' relationship with the person they care for. The carers are motivated to seek help, during which time they are likely to receive a diagnosis and develop a medical understanding of the difficulties, which enables them to externalise and depersonalise the content of the belief. Carers also explore additional sources of support and information to enable them to care effectively, which leads to a broader psychosocial understanding of unusual beliefs.

The adjustment process begins with assimilation of new information, which enables carers to make sense of beliefs from different perspectives. Formulating is a task undertaken by the carer alone for pwd, and is often a collaborative process with pwp. Formulation of unusual beliefs often includes an understanding of what may exacerbate, or trigger an increase in unusual beliefs, and therefore suggest potential strategies for reducing the impact or frequency of beliefs. On recognising these aspects of unusual beliefs, the carer often takes increased responsibility for maintaining a positive relationship, reducing stress for the person with unusual beliefs, absorbs potential conflict and protects the cared for person by concealing their feelings.

Carers with a biopsychosocial understanding of unusual beliefs, having initially felt the beliefs need correcting, adjust their goals to incorporate new understanding. Carers will seek to reduce the impact, frequency, and duration of beliefs, and the conviction with which a belief is held. The will concurrently maximise meaningful engagement and enjoyment. Reflecting these aims carers will seek to soothe distress, validate experience and emotions, and engage a person in meaningful activity and encourage meaningful relationships, and occupation.

To achieve their caring goals, carers of pwd will often 'go along with' the belief and use distraction, often making use of autobiographical knowledge of the person. Carers of pwp invite dialogue and develop collaboratively agreed strategies, which often incorporate supportive exploration of evidence for and against beliefs. Carers of pwp also use autobiographical knowledge to judge which strategies may be helpful at different times.

Carers face many contextual stressors, including high additional caring responsibilities, ongoing worry about risk, or worsening of beliefs and other symptoms. For carers of pwd a significant stressor is sleep disruption. The impact of these stressors is moderated by a range of coping strategies which often include self-care activities, maintaining supportive relationships and having other meaningful roles.

Carers who are motivated primarily by relationship and caring values will often be accepting of the content of beliefs and find burden and stress reduced as a result.

Exceptional Adjustment

Two participants, who were caring for their spouses appeared to have exceptional acceptance of unusual beliefs. The carers shared a level of relationship commitment not represented in parent/child or sibling dyads. These carers experienced significant loss of relationship, and their primary motivation was to maintain their very strong attachment relationship. They exhibited strong relationship values.

Although initially hurt by the content of beliefs, they were highly motivated to seek help and alleviate distress. They were motivated to explore many sources of help an information. They could tolerate and absorb conflict and minimise relationship stress as far as possible, while the content of beliefs was ignored. The carers goals were to maintain their role as a trusted person and create a containing relationship that enabled the person to feel safe. A range of creative and flexibly applied strategies were used to achieve caring goals. While they faced many contextual stressors, they did not appear to have an impact on the process of caring perhaps suggesting high resilience in these carers. Despite their resilience these carers are likely to strive to give perfect care, subjugating their own needs to preserve the relationship. This results in high stress when experiencing 'failures' in care and they may need additional support to manage stress during crises or care transitions.

There was a sense of personal growth and an appreciation of people and life, that had not been present before the onset of unusual beliefs for these carers. These carers appear to have adjusted to the impact on the relationship and the impact on the process of caring (by framing as a temporary difficulty) that enabled them to sustain the caring relationship

These relationships were not gender or diagnosis specific.

Poor adjustment

Low motivation, low adjustment (Orange Arrow)

Carer's who have a history of a challenging relationship with the cared for person seem to take on the role of carer due to a sense of obligation and perhaps cultural expectations that they should care. They may exhibit caring values in relation to others, but their feelings towards the person they are caring for will make it impossible for that person to experience the benefits of those values. These relationships will be characterised by feelings of anger or irritation towards the person who is experiencing the unusual beliefs, resentment at the obligation to care, and a desire for the situation to end. These relationships confer a lot of risk for the carer, particularly those co-habiting, as they experience very negative emotions, feel trapped and depressed and may see the end of life as the only way out.

High motivation, low adjustment (Green dashed arrow)

Some carers demonstrate a strong desire and willingness to care, however there may be several factors that reduce the ability to adapt. The barriers to acceptance can be varied, and may include an avoidant attachment style, low caring values, and a high number of contextual stressors which result in reduced access to additional information, and few supportive relationships. Carers may experience an overwhelming burden of care and feel unable to cope with the additional process difficulties presented by unusual beliefs such as relationship conflict caused by belief content, sleep disruption and few opportunities for respite.